



THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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MEETING REPORT

Our Executive Director attended an annual meeting in Washington this past week and our President graciously surrendered his space this issue so a report could be shared.

The National Organization for Rare Disorders (NORD), was established several years ago. (Rare or orphan disorders are considered those with less than 200,000 U.S. people afflicted with a specific problem.) PWSA decided it was advantageous to become a member and involved with this coalition even though their main thrust was to establish a Federal Orphan Drug bill. We felt that this organization will move onto many other areas of interest, many that will more directly affect PWS. We are also continually informed that organizations, such as ours, must work with other related groups to achieve many goals.

Chiefly due to the efforts on one very capable lady, Abbey Meyer, NORD has moved mountains in the past few years, did get the orphan drug legislation, and has continued to move into other areas as well. Abbey arranged many very impressive people for this annual meeting. From this, we wish we could report that a great deal of knowledge was obtained and that great progress is being made in the areas that affect PWS but unfortunately, we can't. While very informative, it is somewhat discouraging to hear much more of what you cannot do rather than we can be done. One of the statements this is shared is funding starts at the top--it starts with the congressional people. Next you hear but you can't go to them

and cry help, you must not only have specific needs but also solutions and fully developed programs on how to create or achieve these solutions. You are also told you cannot go to them with just one specific syndrome, you must form coalitions or alliances with others and approach them in this way.

We did hear two success stories, things that other groups accomplished, but these were accomplished because of "who they knew" rather than from their needs.

We believe PWSA has accomplished a great deal over just the past several years, and this is confirmed at these meetings. We aren't Cystic Fibrosis, who has grossed 32 million this past year in donations, but we aren't one of the many thousands of groups that haven't managed to form a parent support group either. We are gaining ground but there is a great deal left to be accomplished.

We walk away from these meetings more convinced if you aren't fortunate to have a Senator as a neighbor or tennis partner, you are either going to have a very unusual stroke of luck or what is going to be accomplished is what you are going to do for yourself. That may be discouraging, but it is reality.

In talking with other groups, PWSA is moving and we should be proud of what has been done. In the next issue we will share some of the suggestions that were made at this meeting.

ANNOUNCEMENT

PWSA has converted the membership listing to a different computer. Please take a moment to check your address label for accuracy. If we have made an error, or if you would like a change, please mail your label with corrections and it will be updated.

SCIENTIFIC DAY

The Scientific Day line-up looks great. The fact we have enough people interested in making a presentation and enough with information to share, is encouraging. On this same day (the day before the actual conference) Group Home Administrators & Staff and Chapter Presidents will also meet. Registration of professionals is up from last year, which shows us an awareness of the conference, an interest in learning more, and an acknowledgment that PWSA has something to offer to them in education.

We look forward to another good meeting.

BOOK REVIEW

SPECIAL DIETS & KIDS (How to Keep Your Child on any Prescribed Diet) by John F. Taylor, Ph.D. and R. Sharon Latta.

PWSA was approached many months ago to review a few chapters of this book. Marge Wett and Linda Beltran were thanked for their assistance by the authors in the book.

Certainly all of the suggestions in this book do not apply to PWS but we feel it does an excellent job of talking about understanding your feelings, your child's feelings and the diet. Many other chapters go into health care, discipline and seeking outside help.

We highly recommend this book. It is published by Dodd, Mead & Co. of NY.

POACHING IS GOOD FOR FISH & CHICKEN

Poaching, a successful technique for microwave or stove top - helps cut calories.

Poaching is cooking in a liquid (can be juices, water, wine, broths) in a covered dish so the liquid creates a flavorful steam. On the stove top, you must be careful to adjust the rate of cooking --just above a simmer but below a boil. In the microwave, do it at full power. Microwaving is faster than stove top.

Start with a savory poaching liquid, such as broth, wine, or tomato, orange juice. Use herbs liberally. For fish you can add clam juice or lemon juice. Add onion or garlic for flavor.

Use whole chunks, large pieces. Firm fishes are sole, flounder, trout, whiting, pollock or red snapper. If you use a more delicate fish, choose a shallow dish for a single layer.

CHICKEN AND SHRIMP HOT POT

3 cups chicken broth
2 carrots, peeled, julienne cut
4 stalks celery, cut in strips
12 mushrooms, ($\frac{1}{4}$ lb. halved)
2 c. chopped fresh spinach
 $\frac{1}{2}$ tsp. salt, $\frac{1}{8}$ tsp. pepper
1 whole chicken breast ($\frac{1}{2}$ + lb), skinned, boned and cut in thin strips
 $\frac{1}{2}$ lb. medium shrimp, peeled, deveined, & halved

$\frac{1}{4}$ cup each soy sauce & lemon juice
2 Tbsp. grated unpeeled radish
Hot cooked Rice

In 3-qt. microwave casserole, combine broth, carrots, celery and mushrooms. Cover and microwave at full power 8-10 mins., til carrots are barely tender. Add spinach, salt, pepper, chicken and shrimp. Micro at 4-6 mins, stirring every 2 mins., until shrimp are opaque and no pink remains in chicken. In small bowl, blend soy, lemon, radish. Serve soup in bowls with sauce on side for dipping. Serve rice on side. Serves 4. 1 serving=2 veg. exchanges, 4 lean meats. 213 calories.

"Cover Up Tips for the Microwave"

a brochure including recipes, techniques, defrosting chart, guidelines etc.

A free copy is available by writing, Cover Up-Tips for the Microwave, Box C-32003, Dept. FE-64
Richmond, VA 23261

CONGRATULATIONS

The State Council on Developmental Disabilities (California) grants annual awards to people who deserve special recognition for their work in the DD field. In addition to those who provide, they also award an "Outstanding Consumer" award. The 1986 award was just awarded to Greg Shetrone of Westminster, who has PWS.

Greg, 36, was given this award for "his exemplary devotion and dedication to his job as a volunteer". Greg's manager said, "Greg has done a wonderful job of learning and working independently. At first, I assisted Greg each time he came to work, but now he signs in, goes to work and signs out without my assistance".

We are proud to add our congratulations.

IT CAN BE DONE

Protection and Advocacy represented a client with PWS who had relatively good verbal skills and an I.Q. in the 80's. The administrative law judge who heard the case found, in accord with Protection and Advocacy's position, that, although he was not mentally retarded, this individual was nonetheless developmentally disabled and thus eligible for regional center services because his condition comprised a substantial handicap and because his treatment and service needs were similar to that required by mentally retarded persons.

Another step forward.

SPECIAL PEOPLE BOX

This issue we would like to thank:

DONNA CLUBB for her 2nd large fund raiser for CIT
THE KY CHAPTER for their efforts on behalf of PWS and sharing
DR. VANJA HOLM upon her retirement from the board but continuation of interest in PWS.

MEETING NOTICE

Prader-Willi Syndrome Association of Australia (Victorian Branch)

2nd National Conference - Melbourne

To be held at the Royal Children's Hospital
October 17th-18th, 1987. Enquiries:
Mrs. Diane Barber (03) 870 8428

GROUP HOMES - PLEASE RESPOND

PWSA has been contacted by a dietician who is very interested in developing dietary guidelines for PWS. She would like to network with any group home that is serving a resident with this syndrome.

Please contact: Carolyn Hoffman, R.D.
Central Michigan University, WI 209
Mt. Pleasant, MI 48859

A MEMBER SHARES

A member has recommended a 100% pure olive oil soap for PW use for skin and hair. "Dry skin melts away and it is of long lasting duration. No more itching, no more picking." Mrs. Murray states there are two companies making it that she is aware of: Kiss my Face, 8 oz bar, \$2.75 and Olivea, 4½ oz bar, \$1.50. If you are not able to locate it, Mrs. Murray would be happy to help:

Lois P. Murray
6716 Jade Park Ave.NE
Albuquerque, NM 87109
(505) 821-5946

OUR SYMPATHY

PWSA extends sympathy to the family of Wendy Virnig, an Oakwood Resident, who died this month of Leukemia. Wendy was one of our "workers" who helped colate, staple and label our GV's each issue. She was particularly fond of preparing the envelopes for the foreign copies.

The Oakwood Residence, which is a model for a well operated PW home, is in existence today because of the great amount of assistance from the Virnig family.

We share their sorrow at this time.

CALCIUM SUPPLEMENTS???

A parent requested our opinion on calcium supplements for PWS. Unfortunately, some doctors and nutritionists voice "opinions", they have them just as we do--and not everyone agrees. Not too long ago, antacids were recommended as calcium supplements and it was stated they certainly couldn't hurt anything, but a recent article stated antacids can block calcium absorption, and can also be constipating. So, at the moment, all we have are opinions. There are a few items most people agree on:

...Rich sources of calcium are skim milk, low fat cheeses, sardines, canned salmon with bones, almonds, tofu, collards, kale and other dairy products -- and natural is always better than supplements.

...A 15 minute brisk walk in the sunlight.

...Take a multivitamin-mineral supplement (two-a-day is better) if dieting.

...And certain mineral waters have been added to the list.

If some of our PW experts would like to share their opinions, we would be happy to pass them along.

9th Annual National Conference

June 18-20 Houston, TX

Pre-conference day: June 17th

for Scientific presentations, Group Home personnel, & Chapter President's meetings.

4 FULL DAYS

OF LEARNING,

ENJOYMENT,

CARING & SHARING.

Continental is our Official Carrier - to obtain their rates and discount call 1-800-445-0632 and give them I.D. #Z-1233. (In TX, call 1-800-392-5179.

IT'S NOT TOO LATE (To lend your support in keeping conference prices down)

Tickets can still be ordered, but stubs must be in by JUNE 8th. Unsold tickets can be returned, take a chance and see if you can be a good salesperson.

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

If the tickets are for personal use, just let us know, we'll type in the stubs and enter them for you, saving us both mailing costs.

Our odds are better than any other game in town!! Return this form today.

ORDER FORM:

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

NAME _____ ADDRESS _____

The \$1.00 must be in U.S. funds or adjusted. This is also a fund raiser for your local chapter as 25¢ is rebated locally.

ENCUMBANTS RUNNING FOR RE-ELECTION TO THE BOARD OF DIRECTORS

Dr. Cassidy is a Pediatrician and Medical Geneticist who is an Associate Professor of Pediatrics at the University of Connecticut School of Medicine in Farmington. She has been interested in PWS since her training at the University of Washington in 1980. After moving to CT, she established and is the Director of the PWS Clinic there. Dr. Cassidy helped establish the PWSA, CT Chapter shortly after her arrival. She was a program planner for the PWSA Conference which was held in CT in 1985. She is the author of several articles which appeared in medical journals concerning PWS, the result of research into the disorder. She is also the author of a monograph on PWS which appeared in Current Problems in Pediatrics in January, 1984. Dr. Cassidy has been on the Board of Directors since 1984.

Dr. Cassidy would very much like to continue on the Board of Directors for another term. She feels that her contribution may be valuable both because of her professional knowledge of the disorder and because of her interest in issues which relate to multidisciplinary care of people with PWS. The Board is currently composed of a good mixture of people with personal and professional interest in PWS, and she feels that this helps assure that PWSA remains responsive to the needs of the families and maintains its role as an educator of the public about this disorder. In addition, a position on the board allows Dr. Cassidy the chance to continue her involvement in helping to mold research efforts relating to PWS.



Dr. Wett, a parent and a physician, has also decided to seek another term on our Board of Directors. When approached regarding this matter, Dr. Wett wrote: "I have decided to run for re-election to the PWSA Board, a Board I have served on since 1978. I feel continuity, as well as new members and new ideas, are important to the success of an organization.

As a parent and physician, I have worked closely with the other board members while PWSA has grown from a small organization to a more complex corporation. I feel my expertise can assist future growth. Therefore, I ask for your vote in order that I may serve another term, and to help PWSA in its work of educating the public and professionals."

There are three board positions open. The two above encumbants have chosen to run again. The third, Dr. Vanja Holm, wrote: "Even though I certainly have enjoyed my three terms, I feel that the board now needs people with skills I do not possess. I have done what I can, my part is finished. The play, the history of our association, is splendid, I am proud to have had a part in it, but there are many talented people waiting in the wings, ready to get into the act."

She continued, "(the board) needs people who know about money raising, accounting, law, organizational structure, Robert's

Rules of Order, and many other things that are not my strong suit. So - I am not running for re-election, with some regrets."

PWSA receives this decision with many regrets but understands Dr. Holm's position. We hope some of our members will use this opportunity to give some thought to locating a very qualified person to fill this opening.

More information regarding this process is included in this GV.

PROXY VOTING

PWSA has been asked to explain the opportunity members have to participate in voting even though they cannot attend the annual conference. As a member you are allowed one vote as an individual or organization and two votes for family memberships. This proxy may name a person to vote for you as they see fit or you may request them to vote as you specify. Your proxy must be someone who is attending the meeting.

The major vote that will be taken will be elected three members to the Board of Directors. It is also possible some other policy decision could be discussed and voted upon. By submitting a proxy vote, you may play a part in these decisions. It is important that all of our members play a role in the running of this organization. This is your chance to have your say this year. We have enclosed a sample of how this proxy can be used, you may use one of the people named or you can write in your choice. You may signify how this person should vote for you or you may let them vote for you.

We hope that members who cannot attend will use this opportunity and submit these proxies to PWSA before the first of June.

PROXY BALLOT

I would like the marked delegate to act as my proxy in all voting transpiring during the 1987 Annual Meeting:

| | |
|--|---|
| Lota Mitchell, M.S.W., PA, Board Chair _____ | Delfin J. Beltran, M.D., CA President _____ |
| Fausta Deterling, MN _____ | Harvey Bush, CA Vice-Pres. _____ |
| Gene Deterling, MN _____ | Roy Smith, CT Treasurer _____ |
| Vanja A. Holm, WA _____ | Marge Wett, MN Exec. Director _____ |
| Richard Wett, M.D., MN _____ | |
| Stewart Maurer, CA _____ | Choose one of the board (to the right) or |
| Dorothy Thompson, QMRP, MN _____ | any of the above officers, or you may |
| D. J. Miller, PA _____ | name someone who will be attending the |
| Suzanne Cassidy, M.D., CT _____ | meeting as your delegate. |
| Ted Briggs, TX <u>X</u> | _____ |
| Louise Greenswag, Ph.D., IA _____ | Your write in choice. _____ |
| Janalee Heinemann, MSW, MO _____ | I would like my delegate to vote on my |

Date: 5-20-87 (must be returned to PWSA before 6-1)

Signature(s): your name

Be an active member! Show you care. It just takes a few minutes to complete and mail.

This is how you could use this proxy.

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| | |
|--|---|
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| Gene Deterling, MN _____ | Roy Smith, CT Treasurer _____ |
| Vanja A. Holm, WA _____ | Marge Wett, MN Exec. Director _____ |
| Richard Wett, M.D., MN _____ | |
| Stewart Maurer, CA _____ | Choose one of the board (to the right) or |
| Dorothy Thompson, QMRP, MN _____ | any of the above officers, or you may |
| D. J. Miller, PA _____ | name someone who will be attending the |
| Suzanne Cassidy, M.D., CT _____ | meeting as your delegate. |
| Ted Briggs, TX _____ | _____ |
| Louise Greenswag, Ph.D., IA _____ | Your write in choice. _____ |
| Janalee Heinemann, MSW, MO _____ | I would like my delegate to vote on my |

Date: _____ (must be returned to PWSA before 6-1)

Signature(s): _____

Be an active member! Show you care. It just takes a few minutes to complete and mail.

ACTUAL BALLOT

DONATIONS

We instigated two fund raising efforts around the beginning of this year. One was a mailing of envelopes to our membership requesting support for the Crisis fund, Research, or General Operating. The second effort was the re-contact of friends and relatives.

Although the amount of money received since January 1st has not been low, we could not classify that our efforts have been successful.

.....179 friends and relatives gave \$8423. to the Crisis fund. (179 out of over 1,600 contacted and \$2000 was from 2 people)

.....101 Members responded with \$11,173. to the Crisis fund. (101 out of over 1350, and \$4000. came from 5 donors.)

.....71 donations have been made to the Research Fund, amounting to \$2126, and the general operating fund response has been minimal.

As of the 24th of April, the totals are now:

Research Fund \$ 12,514.56

Crisis Fund \$ 179,282.05

WE ARE STILL IN NEED OF \$20,717.95 TO HAVE THE \$200,000 FUND FOR THE C.I.T.

We do sincerely thank the people who do make their own personal donations, make the effort to supply names for outside contact and do fund raising for our causes. Without your assistance, our organization cannot continue to move forward.

Donations received the end of February, the months of March and most of April include:

RESEARCH: Scalia memorials: Daly, Weichert Synderholm, Sunseri (2), Ollerdesen, Wilson, Dal Porto, Barsten, Butts, Berglund, and Capowski. Other donors were: U.W. of DC, Groenboon, Lehman, MacDonald, Sturgis, Hinson, Abbott (Osakis), Lennhoff, U.W. of Dayton, Kier, U.W. of MI, Fick (Lyon), White, American Institute (Omrod, Mailloux, Monrig, Rose, Nobles and Marsh).

GENERAL OPERATING: Childers, Linonis, Lehman, Sturgis, Kier, White, May & Bennett.

CRISIS FUND (CIT)

Members: Mays, Wett, Mitchell, Dixon(2), Kier, Brewi, Krebsbach, Fulton, Rose, Krempel, Sojka, D.White, Dam, Castle, Kowna, Clubb, Wyka, Lehman, Linonis, Sturgis, Boyd (2), Wolcott, Hinson, Sharp, McAndrew, Davis, Lincoln, Parent Berton, Beltran, Veziroglu, Mears (2), Deterling, E.Olson, Barkeley, Schauer & Bishop.

Friends and relatives:

Mays (Bristol) Flick (Giorgi 2)
Englund (Lynch, Alm) Wolcott (Whitty)
Hjort (Hjort) Gilmore (Voorhees)
Wett (Herman, Bucknum, Wett, Zoia,
Larson, Brandstetter, Schaefer, Hill)
Gottschalk (Merrill) Noordzy(Stickley)
Mitchell (Dodds, Mitchell (2), Wilder,
Cosgrove, Echols) Lynch(Battaglia)
Vermeulen (Roosen, Vermeulen (2),
Hoffrichter, Lenithan, Kappler, U.W.)
Novak (Schoepe (2), Kokoszka)
Youngblood (Peppas, Beecheler)
Doolittle (U.F.) Nanzig(Duncan,Valliere)
Brewi (Brewi (2), Lapreziosia, Rocco,
Moore, DeDora, Smocer)
Howe (Howe, Nickelsen)
Ingalls (Newman, Cole, Wentworth,
Young, Jones) Maurer(Braunreiter)
D.Miller (Brusch, Rossi, Evans, Bowen)
Forthman (Kelly, Fritz, Howanic, Brooks,
Nicholaou) Hutchins(MacLeod,Giles)
Ouilette (Foley, Bender)
Krebsbach (VFW) Krauss(Neugent)
Thomas (Trump, Thomas)
Baletsa (Spsychalski) Battersby(Newell)
Haller (Zahler, Haller,Adrien (2)
R.Bell (Bryant, Nichols)
Ulland (Siena) Maas (Maas 2)
Van Zomerer (Diehl) Eager (Eager)
LaBella (Mulcrone, Salo, Marek)
Sojka (Swenson, Harder, Abramek,
Uzendowski (2), Mojka)
Reiss (Weinburg) Hamisch (Hamisch)
Welch (Bosworth, Gildea)
Hiatt (Miller, Young) Olivo (D'Elia)
Castle (Graham, House) Tobin (Trask)
S.Hall (Singman,Dietz) Gulling (2)
Umbaugh (Reedy, Klatz)
Noll (Noll, Gomeringer, Smith, Rienzo)
Wyka (Gonda,Wallace,Walczak,Nieglos,
Wyka, Vuz) Burleigh (Bowles)
Lehman (Hodgin, Baylor, Beck)
Cohen (Tippett) Abell (Reinert)
Hadsall (D'Alessandro) Cortellini(Falisi)
Evetts (Redling,Evetts,Henderson)

Sheeran (Sheeran), Turner (Townsend)

OUR MANY THANKS

Breneisen (Crotti,Breneisen), Klein (Ciulla,McKoen), Geller (Meyer P.T., Geller),
Townsend (Beta Psi), Barkeley (Lear Siegler),
Heinemann (Bunch), Knippenburg (Faherty).

LAST ISSUE - COMMUNICATION

"I was just reading over the March-April edition of the GV and your article Communication-Cooperation was very helpful for me, I just wished I would have read it 6 months ago!"

The mother continued that they had removed their son from a treatment center because they followed their emotions - "We thought with our hearts and not our brains"

In reviewing what transpired with this treatment, we feel there were definitely problems on both sides (the parent's emotions and the treatment advocated by an organization that is interested in PW but not that familiar). Fortunately, we have been very encouraged lately by more and more reports that the professionals are learning more about PWS. We have talked with several people in the fields of dietetics, education, medicine, etc. that have stated, "PWS is unique. These people and their problems cannot be treated the same as other MR clients." Isn't that refreshing to hear - we have been saying it for years.

This mother continued that they are not capable of keeping their child at home and yet it is so difficult to "let go". In the addiction jargon, it is known as "tough love". Accepting that placement outside of the home is best for the child, that it is a learning or a treatment placement, not that you are shirking your responsibilities, takes a love that is not easy to accept.

PWSA feels that the growth that has taken place with our organization, the development of successful chapter systems, the growth in knowledge of the syndrome, all are influencing better care for our children. We also feel the creation of the crisis center is going to be a giant step forward.

UPDATE ON THE CRISIS CENTER

The wheels of progress turn very slowly, and when you know of a tremendous need for them to move more swiftly, it can be difficult to wait, but waiting is what we are doing with our Crisis Center.

We have approximately 30 young people who are considered in need of a crisis placement right now, and there is nothing available for them in their own area.

PWSA, working with the Laura Baker School of Northfield, MN, has won the approval for the facility to be constructed in that area. Following the county approval, the application was made to the State and hopefully within the next week or two, we will be able to win their approval.

This would be followed by the finalization of fund raising plans of Laura Baker and completion of the building design. PWSA has agreed to furnish \$200,000. and Laura Baker will match that amount for the construction of the building. They are hopeful for ground breaking in September, we are still hoping it could be sooner.

It would be tremendous if we could announce at the conference that all of the requirements had been met, PWSA had raised the balance of their needed funds, and Laura Baker has completed their drive and the building could now be started.

For those unacquainted with the Crisis center concept, PWSA started a major fund raising efforts several years ago because of the need to serve our members. When we were unable to come up with sufficient funds to do this center on our own, we found an alternative plan in working with an existing residential school.

Laura Baker has been serving several young people in their residence successfully and are very interested in developing this new facility exclusively for PWS.

Unfortunately, there is always the miles of red tape to be plowed through first, but we are very optimistic that we will get the necessary approvals and plans can proceed in the near future. We are convinced saving the lives of those in crisis, developing transitional beds and offering respite care, as well as the rest of the by-products of this Center, is worth any amount of effort and WE WILL DO IT.

DEVELOPMENT OF PROPER PLACEMENT FOR PWS

Thanks to the "caring and sharing" of our health consultant, Dorothy Thompson, and the financial encouragement of a generous anonymous donor, PWSA has developed a 200-page booklet of information for those opening group homes specifically designated to meeting the needs of our young people.

The first 18-pages contain an introduction, an explanation of why the booklet was developed, and these couple of paragraphs:

"Why are these homes needed?

An important aspect of any family life cycle includes the progression of time when children must move on to their own life. This moving on time could possibly occur sooner with a child with PW than with a normal child. Prior to 1980, residential arrangements for older adolescents and adults with PWS were not seriously addressed. Due to the lack of proper treatment, very few young people survived to reach the stage of moving on. Typical causes of death for young people were respiratory and cardiac complications, secondary to obesity. With the educational advancement, spearheaded by PWSA, parents and professionals found this short lifespan could be lengthened with proper care. Long-term care needs now exist and must be faced. Previously, many children remained with their parents because a proper placement was not available. These children are now adults in their thirties and their parents are the ones who are "aging out". Others, often younger, are reaching crisis situation because they, too, do not have an opportunity for placement, and their parents and families are "burned out". Behavior problems, as well as escalating weight, can cause crisis for families, when the child remains in the home.

The success of many homes, developed strictly for this syndrome, have shown proper placements can be accomplished. A good placement can be achieved. Although we do have one home that basically operates under the assumption that people will move on, most providers realize they are opening a permanent home.

There is a need for placement of school-aged children, as well as adults, but the need is not nearly as great since many parents are not willing to place their children away from home at a younger age.

The one PWS home, mentioned above, was basically opened as a temporary treatment center, hoping to return the young people to their own home. They wrote: 'the behavioral characteristics accompanying PWS are different and resistant to change'. This statement enforces the point that specific homes need to be developed because young people with PWS cannot adjust to existing programs. Another statement made by this home, 'Not all individuals with PWS need, or will respond favorably, to community-based residential treatment of this nature. A continuum of residential treatment alternatives is needed for this population.' While we agree alternative 'treatment' is needed, we strongly feel a home specifically opened for adults with this syndrome (if operated properly) will meet their needs. We have witnessed many young adults who were literally 'dragged' to a placement, and later (very rapidly) adjusted very well. Outside of a few higher functioning people who talk of living independently, we can easily say residents with PW are very happy in their placement. PWSA is also working on developing transitional programs to meet these needs.

From that section, the booklet continued on with an explanation of the syndrome using many of the materials we do have available. The next section included "Points that need to be addressed in any group home development", followed by "Points that need to be addressed in opening a PWS group home".

This section includes a description of determination of need, the size, finances, location, the floor plan (with complete description of all rooms), furnishings.

Another section goes into the staffing requirements, which is a very important part of looking for success.

The next section, Dietary Needs, includes: "Hyperphagia (excessive, compulsive eating) is one of the major reasons why group home living is essential for a person with PW. Studies have proven that not only is the person with PW a compulsive eater, but gains weight on approximately one-half of the calories that it takes another person.

DEVELOPMENT (cont.)

When one of the first homes specifically for PW was started, the parent group felt dieting would be one of the major issues in trying to operate this home. It was found in a very short time that as long as meals were well planned, contained larger quantities of low-calorie foods, served on a regular basis with two snack allowances and soda pop, the residents were very content with this part of the program. It seems that knowing the food is not available, knowing they will be fed, knowing everyone there is in the same situation, made these young people very satisfied with the food service.

We feel a consultant dietician should be on staff, but this person must be acquainted with PWS. Dieticians have been resistant, as other professionals, in accepting the differences with this syndrome. At the present time we have several dieticians that are working with existing PW homes and they are very interested in networking with other staffs in order to develop some realistic guidelines to be used. A very limited amount of published information now exists and great concern is being expressed about how fast the initial weight loss should be, how to establish realistic goal weights, what should the caloric level be for weight maintenance, and what part does exercise play in these figures."

Another section, Self-esteem/Sexuality reports: "Lack of self-esteem has been heard more frequently as these young people progress in the school system and enter group home living. This is certainly understandable, particularly in the young people with higher I.Q.'s. Not only has the lack of knowledge entered this picture but the fact that these young people do not 'fit' in our society. From stage one, failure to thrive, to stage two, when they want to eat everything in sight, these young people are confronted with problems. Many never have a school situation that meets their needs, they are misfits because of their abilities in learning, their lack of muscle, their balance problems, in addition to the fact many are already overweight--'who loves a fat kid?'. Most cannot

make it in the regular school system and yet do not fit in the special education programs either. They are constantly bombarded with a food oriented world where they have to maintain a life-long diet. They certainly are smart enough to know they are 'different' and their psychosocial problems are piled on top of the medical ones. Many of these problems are not recognized in childhood and young adulthood, but when they enter a group home problems with psychosocial relations become prominent.

Sexuality is not an issue that has had a great deal of study. A couple of years ago a paper was written on this subject by a professional, based on a questionnaire study. The conclusions from the information shared by parents was, 'The PWS child is not asexual. He has drives and interest in the opposite sex. However, heterosexual interest is lower as level of intellectual functioning decreases. Additionally, family, social, and religious values play a major role.' This subject has been discussed at conferences and it is very obvious there is disagreement between experts and parents in this regard. It is very difficult to determine the accuracy of what is reported by these young people themselves or even by their parents. One doctor reported his 17-yr. old patient was having intercourse with his girlfriend frequently (even though he was underdeveloped sexually), just because his patient said it was so. It would be difficult to determine if this story was told because the boy heard this at school and felt it would make him more acceptable or was it really occurring? Naturally these young people have needs but are they sexual or social? The few reports of motherhood and fatherhood in PW have never been proven, from this and autopsy reports, we believe the patient with true PWS is sterile. Knowing also the differences in emotions, we have been led to disagree with the statement that 'these young people do have true sexual desires'.

The conclusion of the above sections talks about relations in the home setting and sexual education. Additional sections face behavior differences, goals of the homes, program needs, vocational needs and a few paragraphs on medical needs. The appendices fill the rest of the pages.

SIBLINGS AFFECTED

The November-December, 1985 issue of the GV shared a report of four brothers and sisters in one family who all appeared to have PWS. The three surviving siblings are reported as having the typical symptoms but did not have the chromosome deletion.

In the April, 1987 issue of Arch Intern Med, another report of familial PWS is reported. Since the principle author is from Ireland, we are assuming the three sisters reported are from that country but we have asked for additional information. Unlike the Iowa family who were only children, these three girls come from a family of 7 girls and 1 boy, ages ranging from 19 to 34. These girls also do not have the #15 chromosome deletion.

It has been proposed that there may be more than one cause for PWS or possibly subgroups of the syndrome. Among other topics, this is one subject that will be approached at our Scientific day preceeding the conference.

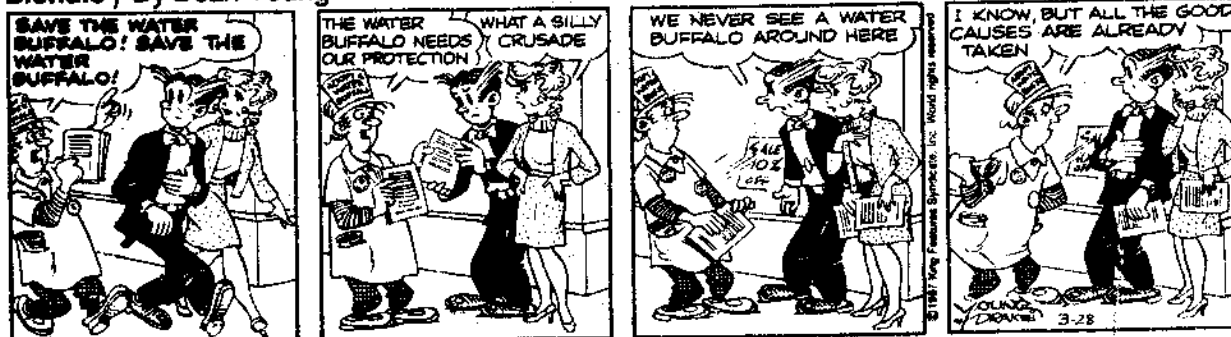
COMMITTEE SERVICE ORGANIZATIONS

A member shared an article written by the National Chairman of the American Legion Auxiliary stating "A good neighbor policy this year with justice for all" suggests that each unit carry on one or two of the most needed programs and add at least one new program this year.

If any of our members are members of the Legion or Auxiliary or know members, here's your chance. Get your local unit to add PWSA as their new project.

From the donations report in the GV, it is obvious we need further assistance from outside sources. Our recent goal of a Crisis Center in 1987 is worth your support.

Blondie / By Dean Young



A MEMBER WRITES

".....Today I was looking at some old pictures of Kristen and she was so fat! Before we knew of her condition we were at our 'wits end' with her continuous appetite and begging for food all the time. I finally got so embarrassed and realized she was just too fat and I couldn't wait for the 'magical time' that people kept telling me would come and she would just all of a sudden 'drop her baby fat'!" (she was 3)

This mother had been sent to a dietician and been told even though her daughter was fat, there really were no diets that they could put children under 12 years old on. Luckily this mother struck out on her own and within one year had a weight reduction of 12 pounds. Three years later, she now has her on the same meals as the rest of the family with small portions. "We still keep frozen veggies, about 4 oz. in each zip lock baggie in the freezer. It's quick, easy, and low cal nutrition. We've learned a lot over the years. We're real happy with Kristen's weight now. We do find that the more we give her the more she'll want so we try to still be very careful. Her eating is the very hardest part for all of us and through hard work and perserverence and always searching for good, quick, easy tips, we do okay!"

Things are looking up. We do have dieticians that are aware of the syndrome and do care about developing proper nutrition within the guidelines necessary for our children. Hopefully, in the not too distant future, we will be able to get more help from the experts rather than us teaching them.

The most important thing you can do for your children is TEACH THEM HOW TO LOVE
(excerpts from a Christopher News Notes, shared by a member)

"You know without having to be told that you should love your children, take care of them, and provide for their material, emotional, intellectual and spiritual well being. But in providing for them you may not be actually teaching them." Jose deVinck, The Challenge of Love.

Paragraphs of this pamphlet include, "Teach love by being patient" - this certainly is not always easy, particularly with our children at times, but you need to convey a message of love even when firm discipline is necessary. "How do you teach patience - by example." "When children have been treated with tolerance and love, when we offer them a listening heart and show interest in their cares,

they not only learn about patience but they grow in self-esteem." We sometimes get too wrapped up in the necessary care part of PWS to remember we are examples.

"Teach love by giving time" We often hear about "quality time" -- communication takes time. Our children require more "listening time" than the average - the need to talk. "Teach love by being tender" Emotions with PWS are different but have you ever seen a child refuse a hug?

"Teach love in discipline" True love involves discipline. A special education teacher once commented, it is hard enough to be handicapped, but handicapped and spoiled is harder yet.

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.

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