

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

Have you ever been so scared that you couldn't even yell out for help? During a recent conversation with the mother of a learning disabled child this point was brought out. This mother, who is also a credentialed teacher, was reinforcing a point she was making regarding her child's disability. For the mother, a temporary and complete breakdown occurred between the recognition of a perceived danger and a normal response to cry out for help from the threat of personal injury by an attack in her own home by an intruder. For the daughter, the breakdown was always present to a variable degree and did not require an unusual stimulus to make the disability become manifest.

This concerned parent never really understood her daughter's language disorder until the day that the shout for help failed to leave her own lips. Because of that experience she was able to understand her daughter's explanation of a taunting experience she had had while on an overnight school trip. Another child sharing the tent had made fun of the girl in a derogatory manner at a time when a supervisory lapse left her without the structured guidance and support she required to cope with her environment. The difference was that fear had blocked the mother's power of expression on a temporary basis where the disabled daughter had a constant inability to gather an appropriate response to most any sensory input. Whether it be the spoken word in normal conversation, the written word of a question, or a life experience requiring a leap from danger or a shout for "Help", the inability existed.

At this year's conference, one parent said so beautifully, "It was not a matter of learning how to live with a disabled child, but how can we live so that our child can live with the disability?" This was clearly defined in our home this summer. Sarah is growing taller and stronger and more bold. During the early weeks following the end of school, her behavior became progressively less controlled, more belligerent, she was gaining weight and we suspected a return of night foraging. Our food cabinets were all bugged with a shrill alarm except a high cabinet, believed to be out of reach. Until one night at two, I awakened to discover that Sarah's new found height permitted her climbing access to the bags of chocolate and butterscotch chips. We extended the alarm system to the extra cabinets and the effervescent misbehavior settled down to a normal roar. We learned to live again within the disability and Sarah's restructured confines returned her to security and permitted her to live in her more normal fashion.

Stress arises when the problem cannot be clearly evaluated in a manner that will permit some form of reasonable solution in a period of time compatible with our daily life. It also arises when the answer is at hand but we fail to act in a timely manner.

President's Message, cont.

First of all the nature of the disability must be recognized and all of the ramifications defined in our own thinking. This occurs with the help of professionals, but mostly it occurs by daily living with the problems and what I would prefer to call maternal instinct as I don't think paternals have been equally blessed. This is the knowledge of your child that makes the family the true experts of Prader-Willi Syndrome as well as other parents of other disabilities. With this type of learned expertise, we can learn to structure an environment that will permit our Prader-Willi person to scream help, without a sound passing their lips.

Delfin J. Beltran, MD

President

CHANGE OF EXERCISES?

Richard Simmons sent us a copy of his latest book as a thank you for us responding to his request for information regarding exercises for physically challenged people. We have heard him interviewed a couple of times for this book and in the conversation he has mentioned PWS as a condition that requires exercise to be a way of life. He also mentioned us in a news interview that one of our members mailed to us.

The book, "Reach for Fitness" is now available in book stores. Simmons has pledged the profits from this book to be used in opening exercise centers designed for "physically challenged" people. The book contains a 107-page chapter with very good illustrations on adult exercises, a 52-page chapter for young children and a couple of chapters on food and dieting. In the Appendix he has donated 100 pages to listing specific disabilities and we are happy to say he included Prader-Willi syndrome. The two pages include paragraphs entitled: Definition, Specific Medical Considerations, Specific Nutritional Concerns, Specific Precautions for a Program of General Exercise and Warning Signs of Physical Overextension. He quotes our Executive Director, "...the best precaution is a complete understanding of your child's abilities and physical challenges. Start slowly with only a few exercises and gradually add activity as your child's skills, confidence, and endurance increase." In another paragraph it reads, "Marge told me, 'Exercise must become a regular part of your child's life, but you can turn him against it if you expect him to keep up with his peers. Children with PW need additional time, practice and encouragement before they can expect to participate in normal activities.'"

You might like to take a look at this book and give it a try.

ARTISTS AND AUTHORS, HERE'S YOUR OPPORTUNITY

One of our younger parents requested a brochure to share with friends and relatives, not like our educational materials but something "light and airy" that would give some explanation of why her child acts as he does, or why she needs the control over his life. How about something entitled, "How the Cookie Crumbles -- into Extra Weight"?

This is your chance, what would you like this brochure to say? Share your artistic talent with some pictorial humor. Give it some thought for a couple of days and drop us your ideas and art work.

 * The Conference Presentors *
 * George & Adelaide Castle *
 * Michael Schaefer *
 * Dottie Cooper *
 * Janalee Heinemann *
 * Judy Goff *

Special People Box

A Special People Box made it's first appearance in the last GV. Even though we know we run the danger of missing some very special people, these are the people we are honoring this issue:

The Conference Presentors -- last issue we thanked the conference workers but neglected to mention those who "care and share" by being presentors (most of the time without any reimbursement of expenses). These people deserve our recognition.

The Castles -- Some times its the little things that count. We beamed when we received an NDC donation from the Castles. They are grandparents who take their daily walk, pick up recycle cans and share the rebate with us.

Michael Schaefer -- a temporary houseguest at the Wett household who is making a monthly donation to the NDC as his way of saying thanks.

Dottie Cooper -- Dottie is an example of many members who "jump in with both feet" when they receive a diagnosis and want to help others. Dottie just spent a tremendous amount of time and effort working with the Sparks Center in holding the first S.E. Regional Conference (which was a big success) and will continue her efforts as President of that new group.

Janalee Heinemann -- See the list of informational goodies in this issue, it includes many articles written by this friend of PWSA. If all of our professionals could step into the shoes of "Mom", I feel we could open many of those closed doors that keep us from solving many of our problems. Keep you pen handy, Janalee, many people benefit from what you share.

Judy Goff -- Some of you had the pleasure of meeting and getting to know Judy, PWSA secretary, at the last conference. Judy is one of these employees who do not put in their time in order to receive a paycheck, but she really cares about her job and what she is doing for us. We are very fortunate to have her as one of our special people.

BETTER THAN A STRING AROUND THE FINGER

A couple of our members have requested that we mail them a packet of self-addressed envelopes so these could be placed with their monthly bills as a reminder to make a donation to PWSA. Regular donations, small and large, are now helping the NDC fund to continue to grow. This past month we have spent considerable time attempting to help a mother in Wyoming to save the life of her son. She is fighting for an out-of-state placement that she knows will be a proper placement for her son but because a local institution has stated they are capable of meeting his needs, funding will probably not be available. When the NDC is operating, we will be able to meet an emergency situation like this and save another life. The PWSA office continues its efforts to reach outside sources of funding but until we can "strike it rich (lucky)", we need to count on your continued efforts to reach our goal.

Drop us a note, we'd be happy to forward some envelopes to you.

In acceptance of some truths which, in truth, are easier to accept than some.

Two poems about our listening disability

Keep It Simply Said
(Our KISS Principle)

I'm articulate giving it out .
I've quite a vocabulary,
But
Not all of your words get in .
What you say is a mystery.

Wanted: Missing Words

Communication problems?
You're just not getting through?
That's because you're saying it.
I'll tell you what to do.
Put it down in writing
So all the words I see.
~~~~~  
Satisfaction promised  
A written guarantee

Poetry from Betty McKeen Poetry for PWS  
available from PWSA, \$2.00



## PROGRESS

Any day now the contractor is going to start converting the PWSA national office from a 13 x 13 room to the luxury of a 13 x 21 room. We don't look forward to the day that the dividing wall has to be removed but we will certainly appreciate the extra room. Some members of the board have been "hinting" (rather loudly) that some of our work could be improved by computerization. If any of our members out there have the necessary contact, we would not mind receiving a donated computer and printer for our use. An IBM or IBM compatible would be the most practical and the printer has to be capable of producing our 1300 labels for the GV. Marge and Judy are not really computer enthusiasts but are willing to give it a go if the equipment could be added. Any possibilities???

## DONATIONS

July and August are vacation months but we still managed to add \$8495 to our NDC fund and \$149.14 to our Research Fund. Our sincere appreciate goes to the following members who continue to support these funds:

RF: Van Zomeran (2); Maurer; Grummer; So NV United Way; Combine Fund of San Antonio; U.W. Capital Area  
NDC: Bintz; Barkeley (Lear Fd); Ingalls (Berthel, Auburn Hi, Amer.Group, Merrill, Stone, Snow, Poland, Auburn Grange); Hambrick; Boston (2); Parent; Dixon (2); Welch (Cohen, Genualdo, Karlson); Wolcott (2)(Bono); Levikoff (2); Huibregtse; Maurer (Smith); Mays (2); Blair; Boyd (2); Forthman (Forthman); Webb (2); Riesenman; Dam; Cohen (Eshenaur, Trippett, Kowal, Cohen); Noordzy (Shippling, McGinn, Harrison, Cornelius); Wett (Schaefer (3); Arnold; Sharp; Hjort; Herrmann; Lynch (Rochester Coke); Stege (Anderson); Canova (Westmoreland); Westbrook; Gottschalk; Beltran; Brewi (Posch); Castle; Levine; Fritsche; and Noll.

NDC donations are entered in the Climb the Mountain Club, which is divided into five divisions of "climbers" as their donations accumulate. This month we moved three families into the next level of their climb: Webb, Castle and Noll. Congratulations on your move upward. We already have three at the peak: Smith, Barkeley and Haller. Now we need to get the achieved goal of funds up there.

NDC funds have climbed to \$135,498.33, which is great!!!!

Research Fund now stands at \$13,519.37, (with \$4000 committed to a research grant that was just approved by the board.)



# INFORMATION GOODIES

We have been asked to share a listing of some of the information sheets we have on various subjects, so this is a listing of some of the items we do have available:

Available for \$3.00 cost:

1. Guardianship and Conservatorship -- defines various types of guardianships and conservatorships (25 pages)

Available for \$2.00:

2. Information on Wills by Roy Smith, attorney. Includes "The Guiding Letter" and samples of wording for necessary clauses to make your will effective in the case of a special child.

3. Development of Proper Placement for Individuals with Prader-Willi Syndrome. Dorothy Thompson and Marge Wett. Comments on existing PW homes, descriptions for physical structure needed, staffing and program suggestions.

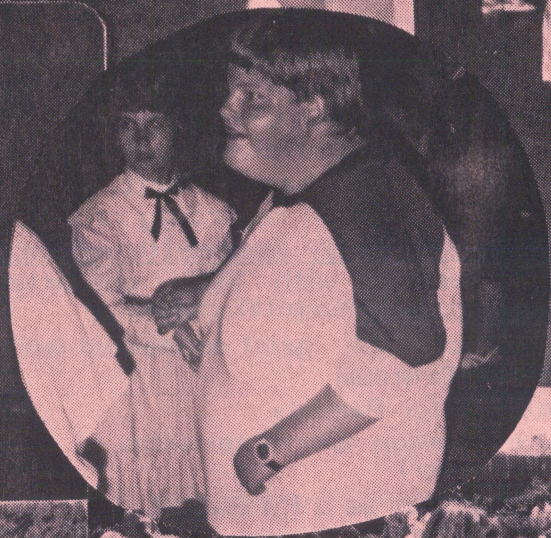
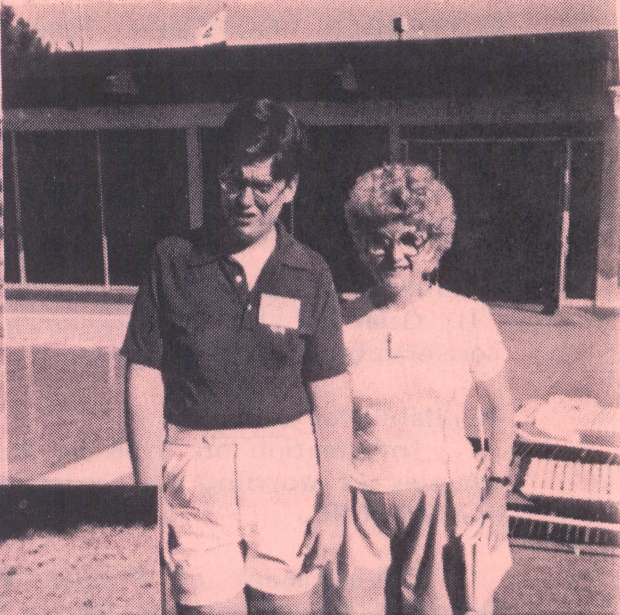
Available at bargain price of 2 for \$1.00:

4. Behavioral Management Programs, Dorothy Thompson
  5. Group Counseling with PW Clients in a Residential School, Jeri J. Goldman, Ph.D.
  6. Oakwood Behavior Project, Charles Evans, Steve Bonfilio, Bob Carlson  
review of study by psychologists on behavior
  7. The Child with PWS Grows Up, Louise Greenswag, Ph.D.  
Synopsis of syndrome, summary report of 232 adult case study
  8. PWS: A Fact Sheet for Teachers and School Personnel, information from Marsha Lupi, Ph.D. and John Porcella, Ph.D.
  9. Synopsis of a Group Home Program for People with PWS, Dorothy Thompson
  10. The Necessity for Homogeneous Group Homes for People with PWS, D. Thompson
  11. Unique Problems with PWS Young People, Marge Wett  
Communicating with other people to dispel stereotypes
  12. Diabetes Mellitus in PWS, Fredda Ginsberg-Fellner, M.D.  
report regarding treatment of diabetes with oral medication
  13. PWS -- The Disabled Child, Richard J. Wett, M.D.  
copy from medical publication regarding raising a disabled child
- And the following list shared by Janalee Heinemann, M.S.W.:
14. Medical Alert for Persons with PWS, characteristics of syndrome, great for sharing with doctors and hospital charts.
  15. Understanding Chronic Grief, grief connected with having a disabled child
  16. Listening Beyond the Tantrum
  17. PWS-- A Life Sentence for Parents
  18. Understanding the Common Characteristics of Brain-Damaged Children (or We Are In This Boat Together)
  19. Keeping Yourself Together as a PW Parent
  20. Caution--Children at Risk! Dealing with the Sexual Abuse of Developmentally Disabled Children
  21. Behavior and Your PW Child
  22. PW Diet Secrets (For Adults Only)
  23. Coming Out of the Closet with PW Behavior Problems
  24. Does a Disabled Child Mean a Disabled Marriage

(You can just order by number if you would like and we'll let Judy have fun filling your order correctly)

Prices are U.S., sorry we'll need another 30¢ per dollar on Canadian for exchange and an extra dollar for overseas postage per order.









### PHOTOS SAY IT ALL

Just look at the photos -- it isn't hard to see the success of the conference. Pictures of the young to the older, joining in the activities, the Big Dance, poolside, friendships, the final day poolside lunch! Wasn't it terrific???

We stuck in a photo of Marilyn Bintz, general chairperson, with a couple of her committee members. Also a photo of Marge presenting a thank you plaque to Dorothy Thompson. A few years back we started the process of honoring some of our very special people at the annual banquet. In the past plaques have been given to co-founders, Gene Deterling and Shirley Neason, and a lady our president fondly calls "Mother Superior", Dr. Vanja A. Holm. This year we honored Dorothy for the many years of service she had donated to PWSA and members. As this is written, Dorothy is in New York for a few days working with the staff of a new group home there. This is just one of many such trips Dorothy has made to share her experiences for the benefit of others. We're fortunate to have all of these great people in our membership.



### SHARE YOUR CAMPING EXPERIENCES

We continue to get numerous requests for camping information, we cannot share what we do not know. Janalee Tomaseski-Heinemann from St. Louis, MO has agreed to compile information on PW camps that will then be available through the national office. How comprehensive it will be will depend on your willingness to help. If you have any good or bad experiences regarding camping programs for your child or group, please respond to the following:

- a) Name, address, phone number of contact person for camp.  
Name, address, phone number of person writing.
- b) Is the camp exclusively for persons with PWS? Or do they have a specialized segment for PWS?
- c) What positive or negative experiences can you relay?
- d) Is the camp available to only people within your region, only people within your state, or anyone nationally?
- e) Length of camp and dates.
- f) Cost of camp. Any assistance with funding?

Please send your response to:

Janalee Tomaseski-Heinemann  
12198 Sage Meadow Lane  
Maryland Heights, MO 63043

### SUGGESTION FROM A PARENT

The conference was a great experience. I picked up the sheet, Behavioral Management Program by Dorothy Thompson. I thought it was so helpful that I checked with the Center where my daughter works, her social worker and the manager of a home and none of these people has seen this sheet. I made several copies and sent a copy to each. I would suggest that all services of PW's would find this invaluable and parents should see that they have this information. *\*see order list - this issue.*

### EASTER SEAL REHABILITATION PROGRAMS

A Delaware mother sent us an Easter Seals newsletter with news about two young adults with PW. She wrote, "This program has been the only program that has been successful in bringing happiness to a person that had been unable to succeed in other settings. I suggest parents seek help from Easter Seals in their states." Her daughter, Lorrie is 25 years old. She had written a letter in the newsletter stating she enjoys the program and that there is hope for people with PWS. Another section stated Lorrie had lost 17½ lbs. in 5 weeks and the other young man, Greg, had lost 90 lbs. in 2 years. Greg and Lorrie are also Secretary and Treasurer of an explorer group at the center.

We certainly wish these young people continued success in their programs.

### NEWEST CHAPTER

We are happy to welcome the Prader-Willi Syndrome Association of Virginia as our 18th chapter. Due to a mail mixup this was a bit delayed but we are happy that their group is now an official chapter.



### CHANGES IN ICF-MR ELIGIBILITY

Federal regulations regarding eligibility for ICF-MR (Intermediate Care Facilities for the Mentally Retarded) do not appear to impede the use of this type of funding for persons with PWS. The rule modifies the federal definition of developmental disabilities by eliminating the functional criteria regarding "gainful employment". Persons with a developmental disability as newly defined who have substantial functional limitations in three or more areas of major life activity would meet the definition of "persons with related conditions" which is stated as being included in addition to mental retardation, or in place of this required retardation. "Persons who have a severe, chronic disability that meets all of the following conditions: (1) The disability is attributable to - (a) Cerebral palsy, epilepsy, or (b) Any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment or general intellectual functioning or adaptive behavior similar to that of m.r. persons, and requires treatment or services similar to those required for these persons. (2) It is manifested before the person reaches age 22. (3) It is likely to continue indefinitely. (4) It results in substantial functional limitations in three or more of the following areas of major life activity: (a) Self-care. (b) Understanding and use of language. (c) Learning. (d) Mobility. (e) Self-direction. (f) Capacity for independent living."

ICF-MR funding is used by many persons with this syndrome in group home settings.

### A NIGHT AT THE MOVIES

There are a couple of movies around right now that warrant your support by attending. They are: "Child of a Lesser God" and "The Boy Who Could Fly". We believe by supporting movies that are based on handicapping conditions we encourage movie makers to feel this subject is financially rewarding as well as something they may do out of the goodness of their hearts. The more the general public is subjected to this type of information, the more they can understand and accept differences.

### OVERHEARD COMMENTS SOMETIMES NEED ANSWERING

"The NDC is just another group home" - we are aware that we have new members all of the time and yet we hate to be too repetitive in the GV. If you read about something and are curious about what preceded this, drop us a line, we'd be happy to fill in the past history. Another way to do this is to order the back issues of the GV and read them - if you just want a year or two, let us know. To cover cost of reproducing and postage we need \$25. U.S. and \$35. Canadian funds, \$40. overseas for all of the back copies but you can order 1984 & 1985 for half of those prices.

The NDC concept is not just to open another group home. This Center was designed to service approximately 48 people, in many cases to literally save their lives, on a temporary basis (1-2 years) and develop a program to meet the individual needs of that person and then work with the parents in developing a proper placement for them in their own state. Another very important portion of this center is to encourage researchers to avail themselves to a golden opportunity of having this many people in one location. This Center would also accomplish publicity and public relations and aid in our attempts to make the name of Prader-Willi as well known as Down Syndrome, Muscular Dystrophy etc. By housing the National PWSA offices in this facility, we could enhance the possibility of our organization remaining a viable group not dependent on availability and affordability of office space.



"I have a 17-month old child and no one has ever asked me to share information regarding his condition for research." For yourselves, PWSA asks you to keep extremely good records of everything that you do for and with your child. These records will be very important to you later in their lives when you start dealing with outside needed services. For PWSA, we ask that any of you who did not participate in our seven part questionnaire survey, to drop us a line offering to do so. We will be happy to add your child's records to the over 600 children we now have charted. Hopefully in the not too distant future this information will be available on computer and will encourage researchers to use as a basis for further study.

"PWSA must make a pile of money on all of these publications" The development of printed materials on PWS was not even considered as a source of income. The very first booklet, Prader-Willi Syndrome - A Handbook for Parents, was really a financial gamble because it cost a couple of thousand dollars to ready for printing and we had no way of knowing if this money would be recaptured through sales. It was developed because it was needed. In further publications that has not changed, we publish or make available anything that we feel will assist our membership either in knowledge for themselves or in educating others. Prices are set to cover the cost of the development, printing, packaging costs and postage. We have allowed a slight "cushion" over these costs hoping that the materials will sell. In all of our publications, except one, we have managed to cover the cost of printing by the sales. The one exception was the printing of "Prader-Willi and You" which has not been a big seller and we still have a large number of the original printing sitting on the shelf. (This is really a shame because it is a good book covering the areas of feelings, diets and activities. It was the request of the authors that it be a bound book and color be used consequently the price is higher than some of our publications.)

Strictly because sales continue to be good, we have come out ahead of publishing costs. What happens to this profit, it is used in the general operation of this organization. This profit is enabling PWSA to retain the low membership fee of \$15.00 per year.



### A PARENT SHARES

MTV really can be helpful! Like many children our daughter with PW, Bethany, 16-yr. old loves MTV. As most parents I first tried to get her interested in other TV shows. Bethany, however, kept turning back to the MTV channel. Before I became overly concerned, we happened to notice an incredible phenomenon. Instead of lying on her bed or the couch (her usual TV viewing position) she was not only standing up, but she was dancing! Bethany loves to dance and by dancing she is getting exercise. MTV is a great dancing teacher! Besides dancing the past several months, Bethany has made a big decision -- SHE WANTS TO LOSE WEIGHT! As of today, she weighs 138 lbs., after reaching her all-time high of 152 lbs. two months before. She likes looking at her weight chart now! I'm now saying, "Hurray for MTV!"

Another parent mentioned his son is "traveling around the world" on his stationary bike. He charts the miles that he rides, traveling from one location to another. This sounds like a great incentive to add on the miles.



## PSYCHOLOGICAL TESTING OF CHILDREN WITH DISABILITIES

Children with handicaps who are in need of special education services must be identified through an assessment process, an important part being psychological testing. There are certain things that parents should bear in mind from the beginning of the testing process. The purpose of testing is to understand the nature of the child and to provide guidance for decisions about the kind of educational programming he/she will receive. Samples of behavior gotten through psychological tests allow psychologists to make generalizations about the child's behavior. No test or group of tests can provide a complete picture of a child's development. Particularly with children with PWS, beware of not basing decisions on a single test. (We have stories of a school psychologist who threw up his hands and said this child cannot be tested, she was sent right before lunch!) Legally, the assessment process must consist of information from a variety of sources. The child must not only be given tests but must also be observed working and playing in natural settings. People who know the child must be asked to provide information about him/her. Together, this information can be used to determine whether the child needs special help, and, if so, to design an appropriate program.

If necessary, adaptations must be made to ensure that a child's physical or sensory disabilities do not interfere with the testing of the child's aptitudes. The law also requires that diagnostic tests be given in the language or mode of communication a child understands. (Several studies have alluded to the fact there may be "input" problems with children with PW and presenting the material verbally and visually may be necessary.) Parents should feel free to ask questions about the techniques being used. (Don't just ask the tester if he/she is acquainted with PWS, give them information prior to the testing.)

Infant testing cannot predict how well the child will function in the future, but do identify children who are "at risk", so monitoring can be started early.

Preschool and schoolage intelligence tests (I.Q.) are part of the assessment process. Tests before the age of 8, may not provide a fair assessment but after that age are considered to be close to those they will have as adults. (Comments have been made that the I.Q. of young people would be higher if the tests were modified but this concerns us that children will be taken out of the mentally retarded funding range and have to battle for necessary special assistance.) An I.Q. score below 69 indicates that a child may be mentally retarded. (Very rarely do children with PW score consistently low in all areas of testing, they have definite areas of strengths and weaknesses.)

Psychological testing is valuable only if it is used as a basis for helping the child function better in those areas where problems are found. Test results should be written clearly so the parents can understand them, if too many initials or unfamiliar terms are used, it is your job to have them clarified.

(excerpts from the NEWS DIGEST, from the National Information Center for Handicapped Children and Youth)

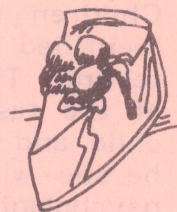
## NEED SOME EXTRA READING?

We haven't seen these books but are passing on the recommendation because the reviews sounded appropriate. "Feed Your Kids Right" Dr. Lendon Smith (Deli paperback, \$6.95), maybe controversial and we recommend reading as a parent of a special child. Karl Menninger's "Love Against Hate", first published in 1942, now available Harvest/Harcourt Brace paperback, \$5.95. Both books are aimed at young parents but are stated to be of value to all.



**QUICK QUIZ**

Are you really up on nutrition??? Try this quiz on for size....



1. Which fruit has more calories or are they the same? Small banana or  $\frac{1}{2}$  cantaloupe.
2. Which has more vitamins & minerals, broccoli, peas or baked potato w/o skin?
3. Is 1 cup nonfat milk or low-fat yogurt equally nutritious or is one more so?
4. Which is highest in calories, cashews, almonds or peanuts?
5. Are margarine and butter the same in calories?
6. Rank in order from highest to lowest calories, grape, orange & tomato juice.
7. Rank in order again, highest to lowest, bleu cheese, french or 1,000 Island dressing.
8. Which is highest in fat? Pizza (thin crust, cheese), fish fillet sandwich or cheeseburger.
9. Highest fat for these three? cheddar, bleu or mozzarella cheeses?
10. Most caffeine, coffee, cola or tea?
11. Highest in Salt, hot dog, 2 oz. cheese, 2 oz. ham?

1. A banana has 100 calories,  $\frac{1}{2}$  cantaloupe 40, both low in fat. 2. Broccoli contains more essential vitamins and minerals than either peas or potato. 3. Nonfat milk is actually higher in nutrients & vitamins than yogurt. 4. Almonds 178 are highest, all are high in calories and fat. 5. Both have 34 calories per teaspoon. 6. Grape 126, orange 90, tomato 36 for 6 oz. 7. 1,000 Island 80, Bleu 76, French 66 per tablespoon. 8. The fish fillet is highest. The pizza contains the least fat and the most nutrients. 9. Cheddar is tops, 9.1 grams per ounce, mozzarella is lowest. 10. Coffee is triple the other two depending on strength. 11. Hot dogs with 627 mg. each. Two ozs. cheese has 400 mg and ham has 32 mg.

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 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 \$15.00 per year for U.S., \$20.00 per year for Canada and overseas. Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.  
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