

The Gathered View

for the younger set

Newsletter of the Prader-Willi Syndrome Association

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Have We Gone Too Far?

by Janalee, from the *Missouri Newsletter*

We are gaining control on Prader-Willi. Many of us no longer let our children terrorize our homes with food demands and behavior outbursts. Our young people as a group, appear slimmer each year at the national conference. But, in our attempt to control a situation that was totally out of control-- have we gone too far? It's a precarious tightrope we parents walk, attempting to keep enough control over our children's weight and behavior and yet allowing them the freedom and independence to which every human being should have a right. This year's national conference expanded our thoughts on providing people with PW situations where they can be more independent. Although I still doubt some professionals' contention that independent living can be achieved, perhaps we need to look at the smaller steps we can take. At the conference itself were examples of situations where we may have "gone too far." Our oldest Missouri member, Phil, is 44 years old (my age). When I first saw him at the conference, he said, "Did you hear the big news, Jan? April dumped me!" (his group home girlfriend). Fortunately, within the first day of the conference, he found a new girlfriend. The next morning, I was called down to the Youth Program because Phil was creating a disturbance. I discovered the reason he was upset was because they refused to let him sit by his new girlfriend on the bus because they had to sit in groups by the order they came in. Phil was crying and kept saying to me, "They treat me like a little kid!" The counselor who set this mandate is 23 years old (my son's age). Looking around at the conference, I realized that complicating the problem for our adults with PW is the fact that with the lack of growth and lack of hormonal changes in puberty, they look much younger than they are. Another example of a controlling situation I question was when my son and daughter-in-law were apartment managers for a semi-independent living program. Each morning they had to "inspect" the residents and their apartments before they went to their workshops. For example, they were to see that their bed was made (with no sheets showing), kitchen counter cleaned, and no more than 3 items on their bedroom dresser. How many of us "normal" adults would pass this inspection? Perhaps we need to look at what is important to control and what we could let go of. One example is the ethical dilemma of locking up food. This appears to be the only way to control food with the least amount of stress for all. Our son has admitted he wouldn't want us to stop locking up food. As our president, Sam Beltran, pointed out at the conference, "If they know there is a way to get at food, they (people with PWS) cannot function as well. They get too nervous and distracted." We agree with Sam, but then a judge in another state ruled that the parents of an adult person with PWS had no right to lock up his food. Perhaps the judge is also right. How would I feel if someone decided that I was overweight and locked up all my food? Perhaps, after a certain age, our adult children have a right to "eat themselves to death." Another "balancing act" we perform is--Do we have a right to tell our adult children with PW what to wear so they appear more socially appropriate, or do we let them wear what they want and pay the natural consequences? The questions of how to best walk the tightrope go on and on. The problem of walking it wrong can have significant consequences.

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President's Message

(Note: Dr. Delfin Beltran lives perilously close to the dreaded San Andreas Fault -- in fact, his home is about 100 yards right off the Fault. The recent earthquake did some minor damage to the Beltran residence, but no one was injured.)

As of last week Sarah's IEP team has met on four occasions since last Spring and no placement has been offered for her education. Each morning Linda drives her fifteen miles to the district office where she has a two hour educational session with the "home teacher." According to Public Law 94-142, Sarah's school district is out of compliance with the law. Our next step is mediation and then on to fair hearing with all the legal conflict that will entail. To complicate life, the IRS elected the day of Sarah's IEP to initiate an audit of my tax returns.

But what really concerns me, and you have probably heard me say it before in one form or another, language, communication, social intercourse, getting on or any number of other ways of talking about how one being transfers thought to another and in the process we learn about one another or about some thing or some idea. The basis of our human-ness is this thing we call language. The level to which the human creature has developed language distinguishes us from them or that. The level to which we successfully develop equality of language exchange between people will determine the level to which we succeed in having successful lives with peace and love and internal harmony. The development of language is as natural to living as a human being as is the process of breathing and just as important to the success as a functionally whole person.

Recently I had the opportunity to hear a lecturer who has dedicated her scientific career to the examination of the learning process. Her first task was to determine a concept that would describe the first critical step in the human learning process. She came to the conclusion that the very first condition that must exist was that the learner must have the mind set to learn. The mind of the learner must be in a condition that is receptive to a new stimulus. You can read these words from the top of the page to the bottom, each word can be seen and recognized as a known bit of information. Each group of bits of information can be processed as a thought and you might learn something. But on the other hand, I am sure because I have done it myself, it is possible to read the words, recognize the groups of words as sentences and paragraphs, then arrive at the end with no knowledge of what the printed words were all about. Either we were daydreaming or we were concentrating on getting something else done at the time or worrying about something in the future, but we were not learning. Our language system was not turned on to the task at hand. External information could not be transferred into our mind. Our language mechanism was not alerted to process new information. Internal mind business was going on and external language could not reach our mind.

What if you had Prader-Willi Syndrome and your genetic make-up constantly kept a switch turned on in your brain that

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Prader-Willi Parents

I would like to share something that worked for us with other parents of young Prader-Willi children. Our PW son, Jeremy, tried unsuccessfully to ride the Fisher Price tricycle a girlfriend of his outgrew. Then, for 3 months, he became the caboose on our train as we rode daily to and from the neighborhood pool and playground 3 blocks away. With his baby sister in the wagon, he and his 2 1/2 year old sister's identical bikes were tied with old pantyhose, one to the wagon and one to the other tricycle. When the wagon was pulled, the nylon gave them the help and freedom they needed to learn to coordinate their steering and pedaling. In July, for Jeremy's 5th birthday, he got a new BOYS Fisher Price tricycle. Two days later he rode it up and down our block alone. I have never felt so much pride. And now, he keeps up, while racing his bike with his sister and 3 and 4 year old friends all around the neighborhood. So many people said he wouldn't ride a bike until he was a teenager. And we have so many tricycles and big wheels in our garage that he couldn't ride. But we didn't give up trying, and this one accomplishment can lead to another.

Potty Training

"I am responding to your article 'Newspaper Sharing' (July-Aug.) As the mother of a 4 yr. + son with PW who just finished potty training, I may be able to offer a way that might work. My son was also not motivated to learn and at times it seemed like a matter of control. Attempts between the ages of 3-4 were not successful. We then made a toy box, filled with inexpensive toys and a sticker chart. The first 2 wks. were 75% accidents but in 2 wks. it clicked in. Every time Tony successfully went to the bathroom he got a special toy and a sticker. When he got 10 stickers he got a special toy or outing. The toy box was emptied twice before we went to stickers alone and then after 2 wks more we stopped them. I found that initially he needed immediate rewards.

I was frustrated with the many books and articles I read. I didn't find any that dealt with a 'strong-willed, unmotivated child' who could not be rewarded with food. My son has only slight learning delays and we are keeping his weight in check. If his routine is upset he can have more trouble with his eating drive.

Group Home Statistics

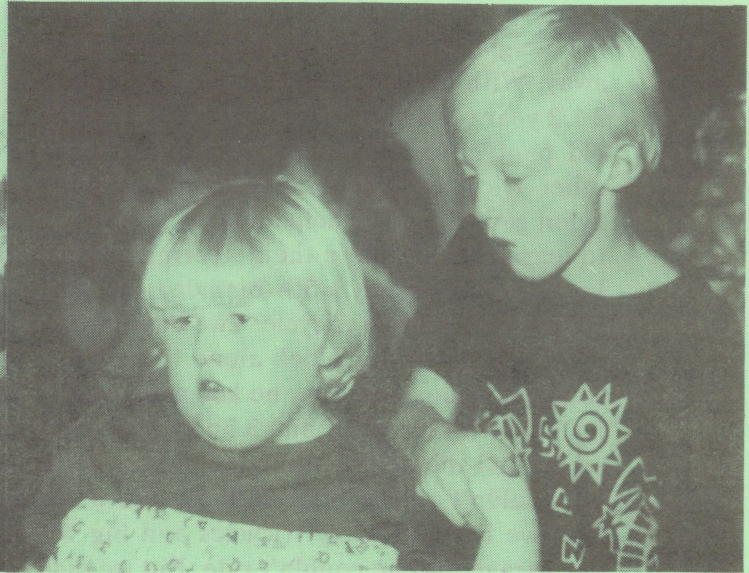
We have statistics on the following homes for persons with PW only:

One person home:	Florida, Canada	Serves: 2
Three person:	Connecticut, Wisconsin	6
Four person:	California, Massachusetts (3), Wisconsin, Hawaii	24
Six person:	California (3), Massachusetts, Michigan(2), Pennsylvania	42
Eight person:	Illinois, Massachusetts, New Jersey, South Carolina, Washington (2), Wisconsin	56
Nine person:	Utah	9
Eleven person:	New York	11
Twelve person:	Missouri	12
Fifteen person:	Minnesota	15
		Total: 177

These are homes and larger facilities who serve at least one person with PW. Located in the following areas: Alabama (1), Arkansas (1), California (6), Colorado (2), Connecticut (4), Florida (3), Georgia (1), Illinois (1), Indiana (1), Iowa (5), Kansas (4), Maine (1), Maryland (4), Massachusetts (3), Michigan (4), Minnesota (5), Missouri (2), Montana (2), New Jersey (1), New York (4), North Carolina (2), North Dakota (1), Ohio (5), Oregon (2), Pennsylvania (5), Rhode Island (1), South Dakota (1), Texas (3), Utah (3), Virginia (2), Washington (1), Wisconsin (1).

Our Family!

We are happy to share a few photos of some of the younger attendees at the last annual conference. Developing an activity program for the over 100 people who attend this program is quite a job but very rewarding when you see what a great time everyone has.



We are also happy to share a photo of Bob, joined by his older sister Jenny and his new sister Sue. Congratulations on the terrific family.



A Parent Shares

I would like to throw out some things that we can do as parents. We concern ourselves too much with our child and forget about ourselves. We need to recognize the importance of our diet, get some medical attention for ourselves, we need to exercise to reduce stress. As parents we need to learn to recognize the stress factors in our lives and do something about it with or without professional help. We need to treat ourselves nicely. We are truly important people, we are the only advocate for our child and if we are down we are not going to do a very good job. Take time out for yourself even if it is within your home. Because we get so busy, because our children require so much of our attention and so much of our time, you are going to feel guilty because you do not do enough for the other children and then you try to compensate for that, giving them more time and the communication between you and your spouse tends to somewhat go away, and the attention you give yourself is nothing. How many times do you say, I am going to take an hour this week just for myself? If you are going to survive, deal effectively with the stresses in your life, I ask you to consider these things coming from a parent of an 18 year old that has survived this far and as the wife of the same man for 21 years. Respite care is wonderful, time not to worry about anyone or have anyone saying "Mom" to you. A: I think that the only thing I would add to that is to have a sense of humor and don't feel guilty about it. Laugh once in awhile at some of those anecdotes that you tell to each other. Yes, there is a suggestion of sadness, but don't feel guilty about laughing about it once in awhile. Parents need humor in their lives, particularly parents of PW. As a wrap up, learn more about personal coping strategies, behavior managing techniques, respite care and the importance of getting away (for the child and you), parent therapy. As the lady said, take care of yourself physically, emotionally, and socially. Take time to design your own therapy program. Participate in parent support groups. Some people have found great consolation and support through religion, I can't undervalue this last one for the PW child as well.

Dear Gathered View . . .

. . . My name is Kevin. I have Prader-Willi Syndrome. I have been losing weight. I've been on W.W. & Fast Food Diet, Richard Simmon Meal & Deal. But I have lost about 10 lbs. from 235 and still losing. I found a diet called Nutrasystem Weight Loss Program. I recommend the people who are Prader-Willi Syndrome go to Nutrasystem Program. It will work. If you drink 8 glasses of water and exercise. My age is 20. Please, I would like to have a pen-pal. My address is 1501 Paisley Dr., Arlington TX 76015. Your friend, Kevin White

Mississippi Parents . . .

. . . Hilda and Lee Winstead contacted our office and asked if we would assist them in contacting additional people to form a parent support group in your state. If interested please contact the Winsteds directly at: Rt. 5, Box 462, Philadelphia 39350 (601) 656-2395. The Winsteds are very interested in establishing a group home. Please give them a call.

Benefits of Respite Care

In addition to providing direct relief, respite has added benefits for families including:

Relaxation. Respite gives families peace of mind, helps them relax, renews their humor and their energy;

Enjoyment. Respite allows families to enjoy favorite pastimes and pursue new activities;

Stability. Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis;

Preservation. Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect and child abuse;

Involvement. Respite allows families to become involved in community activities and to feel less isolated;

Time off. Respite allows families to take that needed vacation, spend time together and time alone; and

Enrichment. Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

PWSA hears from members that the problem is that there is not enough respite available and most of it is not suitable for the majority of families. Problems can also be cost, location, times available and appropriate care/program services. There is also a lack of understanding that there is a need for respite in the case of a family with a PWS person. Often respite programs are designed for children more medically involved than children with PWS. Unfortunately this puts respite in the same "boat" as so many things connected with our children -- sometimes it has to be another "do it yourself project."

The National Information Ctr. for Children and Youth with Handicaps recently donated one of the News Digest to respite. In addition to the comments above, it also outlined basic steps for establishing a program:

Research

Enterprise

Structure

Publicity

Interview

Training

Evaluation

If you or your chapter are interested in further information, please request a copy of this issue from PWSA.

Letter to the Editor

A recent letter to a newspaper editor seemed worthy of sharing:

"Pat Gardner's article May 28 on a Child's Bill of Rights was 'the straw that broke the camel's back' for me. There has been a lot of discussion in our society about children from 'broken homes'. No. 10 in the Child's Bill was the right to recognition of the fact that children involved in a divorce are always disadvantaged parties and the laws must take affirmative steps to assure their welfare. That made my blood boil.

The last thing we need in our society is more 'victims'. Who are these people who say children of divorce are always disadvantaged? Is that the message we want to give our children? It certainly isn't the message I want my children to hear.

My children have two homes. Every other week they pack a bag and live with a different parent. Inconvenienced? Yes. Disadvantaged? No. They are fortunate to have two parents who care about them and want to be with them. There are children in 'married' homes who can't say the same thing.

My children have seen sadness, courage, struggles, honesty, options, love, painful decisions, growth and have learned that people need to take care of themselves. To me the disadvantaged children in our society are those living with dishonesty, abuse, disrespectful behavior, mixed messages, and thinking that there are no options. And children of 'broken homes' don't have the market on that.

Our society has glorified the family and assigned attributes to it that rarely exist. Experts say our society has more dysfunctional families than healthy ones. Who is worrying about children in those families? If we would all be responsible for looking after our own children and providing them with the kind of home that 'others' need, it would be a better world.

How many people can honestly say that their children see them doing unto others as they would like others to do unto them? How many can say that they 'do as they say'? How many are teaching their children how to respect themselves?

I am not excusing divorce and saying it is the 'right way', but it is not always the 'wrong way'. We need to stop kidding ourselves that 'broken homes' are the source of so many problems. Unhealthy parents are the source of many problems."

This letter brings to mind attitudes toward the differences in PW families. It has been our experience to have to sometimes recommend that custody be given to only one family member in the case of a child with PW because of the structure required. It has also been our experience to be involved with families that have been reported to the police by neighbors or others involved who do not understand the ramifications of this syndrome. When faced with some of these problems or decisions, please do not hesitate to ask for help from others.

Call On Us for Cards!

New Member, Sympathy, and Honor Cards Available. The National Office is in the process of mailing a one-time membership card to members as they renew their membership. We also now include a new memorial and honorarium packet (cards) for your use. If you'd like a packet now, drop us a line.

Welcome Aboard!!

We welcome Barbara Harris to the national staff as Assistant Director. Barbara has a social and financial background which will be helpful in the operation of PWSA. We're glad to have her on board.

Clothing for Larger Kids

At Last, Inc., created by two mothers with overweight children, offers clothing for larger kids, which can fit waistlines from 23 to 50" and weight from 55 to 285 pounds. Some of their selections include Zeppelin pants from \$34 to \$38; no-waist dresses from \$36 to \$40; jumpers \$32 to \$36. If you are interested in their catalog it can be ordered from At Last, Inc., Bldg. 32, Endicott St., Norwood, MA 02062.

Minnesota Center for Research on Developmental Disabilities

In August, the National Institute of Child Health and Human Development awarded a five year, \$1.76 million grant to the Institute to establish the MN center. It becomes one of 12 M. R. centers originally established during the administration of President John F. Kennedy to serve as a national focal point to discover ways of preventing and intervening in developmental disabilities. Research will be focused in three areas, one which is of great interest to PWSA, behavior problems. Our director, Marge Wett, has been serving on the Institutes Board of Directors for the past year, and appreciates the Institutes interest in PWS. Marge was happy to attend a reception in October celebrating the receipt of this grant and rubbed elbows with such people that included Duane Alexander, Director of NICHD, Alfred Baumeister, Director of the Kennedy Center at Vanderbilt, Christopher Kennedy, representing the Kennedy family and Jess Thoene, Medical Director of the Joseph Kennedy, Jr. Foundation. In Dr. Thoene's reception presentation he included the statement he was happy to be welcoming a center that was working on conditions such as Prader-Willi syndrome and other genetic disorders.

With the Holidays Approaching . . .

. . . We hope our members will keep in mind our conference fund raiser when looking for that token holiday gift. \$10 gets you a 1990 pocket calendar as well as the opportunity to win up to \$450. We still have lots left!

Annual Fund Raiser - "Be an Angel"

Our annual fund raiser to our membership and other potential donors (which have been supplied to us by members) is about to go in the mail. This is our annual effort to operate "in the black" for the year ahead instead of "in the red." We have obtained promise of \$10,000 in matching funds if we are able to raise at least that amount. We hope our members will feel this effort is worthy of their support. We can also use additional names to contact if you would share them with us.

New Food for Thought by Dan Sperling, *USA TODAY*

A recent discovery in hunger control has whet scientists' appetites. Scientists at Merck Sharp & Dohme Research Laboratories in Essex, England, say they're closer to finding a way to trigger and shut down hunger by manipulating a hormone that occurs naturally in the brain. Results are reported in today's issue of Science. When the hormone-Cholecystokinin or CCK-is released normally, it brings on the feeling of being full. Lower levels bring on hunger. The researchers found they could make hungry rats feel full and full rats hungry. Research was based on the discovery of receptors for the hormone in the brain and a substance that can block them. The study could lead to "medications that would influence appetite," says Dr. Margaret Altremus of the National Institute of Mental Health. These might one day be used to treat compulsive overeating, bulimia, anorexia and loss of appetite in cancer patients.

The Recipe Corner

LOW-CALORIE TAPIOCA PUDDING: 1 egg, separated; 2 c. skim milk; 3 Tbsp. tapioca; 1/8 tsp. salt; 1/2 tsp. vanilla; 4 tsp. Sugar Twin. Mix egg yolk and small amount of milk in saucepan. Add remaining milk, tapioca and salt. Cook over medium heat until mixture comes to a boil, stirring constantly for 5 to 8 minutes. Beat egg white until it stands in soft peaks and then add to hot tapioca mixture. Add vanilla and artificial sweetener. Cool. Stir again in 20 minutes. Makes 4 servings. 1 serving = 1/2 milk exch., 1/2 bread/starch exch.; 88 calories; 11 gm. carbohydrate, 6 gm. protein, 2 gm. fat, 217 mg. sodium, 66 mg. cholesterol and 160 mg. calcium.

CHOW MEIN: 1/2 c. minced onion; 2-1/2 c. chicken broth, divided 10 oz.; diced, cooked chicken or veal; 6 (scant) tbsp. flour; 1 c. cubed celery; 1/2 tsp. salt; 1-1/2 c. bean sprouts; 3/4 c. mushrooms, sliced; 2 tbsp. soy sauce. Cook the onion until tender in part of the broth (about 1/2 cup). Add meat and slowly stir in flour and remaining broth. Add raw celery and salt and simmer 20 minutes. Add bean sprouts and mushrooms and heat thoroughly. Then add soy sauce, if desired. Add extra water if necessary. Makes 4 servings. 1 serving = 1 vegetable exch., 1/2 bread/starch exch., 4 lean meat exch.; 253 calories; 15 gm. carbohydrate, 31 gm. protein, 7 gm. fat, 2010 mg. sodium, 65 mg. cholesterol and 51 mg. calcium.

LEFTOVER LETTUCE: Waste not, want not was the adage in most kitchens many years ago. But back then, no one knew what to do with leftover lettuce salads. Today's cook knows it can be quickly turned into a soup course, presumably for another meal - in a blender or food processor. To do so, puree 4 cups of leftover salad with salad dressing on it. (If a vinaigrette dressing was not used add additional lemon juice). To the puree add 1 cup buttermilk, 1/2 cup unflavored yogurt, 1/4 cup sour cream, 1 tablespoon lemon juice, 1 minced garlic clove, 1 tablespoon minced fresh dill (or 1 teaspoon dried), and 6 tablespoons water or as necessary. Puree the entire mixture and season to taste with salt and pepper. Serve the soup chilled and garnish with diced tomatoes.

SNACKS NEEDN'T BE HIGH IN CALORIES: Make a low-calorie drink by combining soda water and unsweetened fruit juice. Serve it over ice or blend it with ice to make a kind of shake. Marinate leftover vegetables in low calorie salad dressing and eat cold. Combine plain yogurt, 3 tablespoons of low-calorie jam, 1/4 teaspoon of cinnamon and 1 teaspoon of grated lemon rind. Use as a dip with fresh fruit chunks. Mix water-packed tuna, plain yogurt, onion celery, cucumber, pepper, dry mustard and lemon juice or vinegar. Spread on crackers or Melba toast. Make a mini-pizza by putting a tomato slice or tomato sauce on a bagel chip, crisp-bread, English muffin or Melba toast. Sprinkle with Italian seasoning and top with part-skim mozzarella. Put under the broiler to melt the cheese. Use pita bread to make a pocket salad. Cucumber, onion, lettuce, tomato and diet dressing make a great combination. Create instant ice cream. Combine 2 cups frozen (unsweetened) fruit, 1 cup skim milk and 2 to 4 tablespoons of sugar (optional). Place in blender and whirl until smooth. Serve immediate as soft ice cream or pour into plastic cups and freeze for 1 hour.

NO-CALORIE FLOUR: Fiber-rich, low-calorie cakes may become a reality because of research by the U. S. Department of Agriculture. Good Housekeeping magazine reports this month that scientists at the USDA have figured out how to produce no-calorie, high-fiber flour from corn casings, the fibrous skin that hold kernels on the cob. The flour can replace up to half the conventional flour in some baked goods such as cakes, as well as waffles, pastas, sauces, and puddings.

NONSTICK COATINGS: Owners of pans with nonstick coatings (such as Teflon and Silverstone) will be relieved to know that the flaky particles that come off after the pan has been well-used are not harmful. The coating is made of an inert substance called fluorocarbon resin that does not react with the foods cooked in it, according to the *University of California, Berkeley, Wellness Letter*. So even if the flakes get into food, they will pass unchanged through your body.

Have We Gone Too Far?

(continued from page one)

OR IS THAT THE ONLY OPTION? In the first half of this article, you heard from the "professional" Janalee, the social worker who no longer lives with Prader-Willi 365 days a year. I was one of the few mothers who went to the conference refreshed and enthused, and fell for what the other professionals said hook, line and sinker. But, the day after we returned from the conference, Matt our 16 year old son with the syndrome, came home. Within the first 2 weeks, as Al said, we were "smashed into the brick wall of reality." We were working on offering Matt more opportunities at independence, and trying to be especially sensitive to Matt's needs and rights as a person. Also, our older son, Tad, who Matt idolizes, had taken Matt shopping and helped him pick out many wonderful, "cool" clothes. They both came back beaming with pride. Then Tad styled and frosted Matt's hair. Matt was feeling very proud of himself. (at 5'4" and 108 pounds, he should be proud!) Al and I were commenting privately how good we felt that we had children that were so kind and considerate of each other....And then Matt lost it. Basically, Matt got upset over something Al said. It was a statement that would not have bothered any of our other children and should not have bothered Matt. But, he took the comment the wrong way and got stuck on it. He proceeded to get himself so worked up that he pried off the locks in the kitchen, tore apart his favorite art projects, then cut up all of his new clothes! We were horrified, heartsick, at a

loss for "Why?"...and true Prader-Willi parents again. I won't go into further detail on the incident because I don't want to detract from the real issues here, which is that bizarre, awful incidents are not unusual with PWS and the outburst can be blown all out of proportion from the cause. Of course, until now, when hearing of similar PW incidents, we would have said, "Our son wouldn't go THAT far!" In the past, when we have made such statements, we always end up eating our words. And again, we have to humbly say, "We don't know how far he would go!" Of course, Matt is now sweet and contrite, and the reality of this "other personality" is already beginning to fade away because we WANT to believe the first half of this article. We want to be optimistic and hopeful. But, meanwhile we've bought bigger locks and unfortunately, the chains that bind us to the syndrome have become stronger. We've moved all of our irreplaceable items (eg. picture albums) into our home office--which now has two locks. Meanwhile, as we try to regroup, Al and I lay clutching each other in bed pondering: What would make anyone do something that destructive?...What price are we willing to pay to keep control?...How much are we willing to risk to give Matt independence?... How do we make logic out of a totally illogical behavior pattern?...How do you trust and love someone -- yet protect yourself for when the next unexpected blow strikes?

Dream Fulfilled

We are happy to share this article from "Wonderland Camp," regarding one of our PW parents. Charles J. Miller had a dream. He dreamed of a residential summer camp on property owned jointly by himself and his brother-in-law, Harry Brown. This camp would be planned so mentally and physically handicapped children and adults could experience the exhilaration of outdoor living and recreation. Particular attention would be given to addressing special needs of the handicapped in a least restrictive environment. Mr. Miller was more than a dreamer. He set out to make his dream come true. First, he called together interested and concerned groups to discuss his dream. Participating groups were the Missouri Department of Mental Health, United Cerebral Palsy of Missouri, Missouri Association of Retarded Children, Woodhaven Learning Center and Missouri Jaycees. They agreed it was a wonderful and workable idea. Consequently, Mr. Miller and Mr. Brown donated their land - 35 undeveloped acres adjoining the Lake of the Ozarks with an additional 100 acres for nature trails and outcamping. They named it Wonderland Camp and it was incorporated as a not-for-profit foundation by the State of Missouri. On May 17, 1970, the Missouri Jaycees voted to adopt the camp project. Nineteen years later, Wonderland Camp is a complete facility for organized residential camping for both the physically and mentally handicapped. Each year hundreds of campers participate in a camping program designed to meet their special needs.

Conference Papers for Calgary Meeting available

- *Celebrating Differences.* A. Neufeldt, Ph.D. (working with the handicapped). 6 pages. \$1.00 US; \$1.25 Canada & Overseas
- *Home Intervention & Stress Control.* T. James, Ph.D. 9 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Education, I.E.P.s & Other Factors.* T. James & M. Bintz. 12 pages. \$1.50 US; \$1.90 Canada & Overseas.
- *Employment, Some Successes.* N. Martlett, Ph.D. (interviews with people with PWS). 10 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Nutrition.* M. Moreau & M. Gellatly (Moreau presentation, information from Gellatly). 9 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Residential Options.* N. Martlett & D. Thompson. 10 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Intervention Strategies.* R. Clark-Brown & P. Gordon, Ph.D. 6 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Group Home Staff & Parents Discussion* (pre-conference). 29 pages. \$3.00 US; \$3.75 Canada & Overseas.
- *Support Groups.* J. Hicks. 5 pages. \$1.00 US; \$1.25 Canada & Overseas.
- *Scientific Day, abstracts of papers.* 14 pages. \$2.00 US; \$2.50 Canada & Overseas.

A complete set of the above papers cost \$8.00 US; \$10.00 Canada & Overseas surface (\$17.00 Overseas airmail)

President's Message (continued)

told you to think about food. Sometimes your mind would mindlessly rumble around thinking of what you had for breakfast. Sometimes that gene switch would pick up signals from the smelling centers of your brain that Johnny's lunch was behind the closed door of his locker across the room. Then your gene switch would get a signal from your internal clock that it is time for the snack that was promised. And on and on and on throughout your entire day. That infernal gene switch kept dominating your entire life, whatever you did it would be there stimulating you to think about getting food. But unlike the gene switch that makes you breathe in and out, your mind is never free of thinking about doing it, your mind is constantly alerted to that food-seeking. It doesn't just happen that there is food to eat and you can ignore the process as your mind ignores breathing. The process of getting more food to satisfy the gene switch is an active thing that cannot be forgotten or ignored. It requires active and aware conscious effort to find the food before it can be taken in to satisfy that need. It is a constant mental and physical and biologic and physiologic and all consuming process that makes other mental processes impossible or at best improbable.

How many educators exist who have even the faintest concept of what Prader-Willi Syndrome means to the education of your child? Sarah's reading teacher last year told her mother that she had heard about language and that some day she intended to take a course in language. The lecturer referred to above asked a state level administrator in California's educational system, "Have you ever tried to teach without using language?" That was in response to the educator's plea for more time for training teachers so that a course in language could be fitted into their busy schedules. Reading and speech are only a part of the manifestly apparent signs of language. The hidden deficits that encumber the lives of Prader-Willi Syndrome persons are the untaught deficits of the educational system. So it's off to court. If I'm lucky the experience will be restricted to the educational arena. -- *Delfin Beltran, MD*

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