

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S REPORT -- "PUBLICITY"

According to our by-laws of incorporation, the Prader-Willi Syndrome Association was formed, "to act as a vehicle of communication on Prader-Willi syndrome related matters..." (Article II, Section I.) The Gathered View is the primary vehicle to accomplish this purpose. Each issue is published with the purpose of fulfilling this expressed goal. It is the only source of information published on a regular basis for persons concerned about Prader-Willi syndrome.

At the recent Houston annual conference, the suggestion was made that the Association should establish a goal or undertake a project that can involve each and every member of the organization. What was needed was for all members to become involved in a communal goal that could be identified by the members. At the same time, it should advance our goals and purposes. During the discussion it was noted that the current drive to establish a crisis center held all of the earmarks of the type of activity under discussion.

Another suggestion was a national search to find an angel for the Association. That is find a person with a national recognition that would take us under their wing and help with the creation of a national image for PWSA. It was apparent that considerable effort had been expended in this area with very little to show for it. Another suggestion, what is really needed is for the national office to wage an information campaign on the medical profession. Then every physician who came across an undiagnosed person with PW would be able to produce a prompt diagnosis. Then that family could be saved the hardships that occur without a guiding diagnosis.

A popular recent suggestion has been to change the format of the Gathered View so that it would be more like the quality reports that we see from many other national level groups. It was promptly apparent from a quick review of current budgetary problems that any changes that develop greater costs cannot be implemented. Some persons even suggested that a national effort be made to ensure that people did in fact read the GV.

One year ago, at the first meeting of the committees of chapter presidents, time was spent discussing the meaning of the terms publicity and public relations. One group volunteered to become the committee of Publicity. A task of this committee was to have been the definition of terms and tasks that could be accomplished. Like so many prior attempts to develop committees, this too, did not succeed. The enthusiasm engendered at the National Conference is difficult to translate into action when the attendees return home.

On the other hand the enthusiasm engendered at the meeting was based on reports of people who have accomplished many great things. New homes have been created where there were none. This has involved people that have never heard of PWS before. People responsible for making decisions important to the care and support of persons with PW are exposed to the name and can then identify the name with real people who have sought their assistance and for whom they have had to make a decision. In other cases, people have bought raffle tickets and the seller has been in the position of explaining the syndrome. Medical and educational persons have been contacted for support who had never heard of PWS before and were faced with the problems of management in our concerns. This past summer we went to a pediatric psychiatrist for help and he was able to report his prior experience with one other PW person during his earlier years of training. Importantly, he has become reintroduced to PWS and enthusiastic about the possibilities of applying his skills to a new challenge.

Failures and successes go hand in hand. It is good that we consider a national group goal. It is important that we develop new challenges. It is necessary that we continually undertake new tasks. Every effort that we as individuals and members of the group make to solve our individual problems, results in contacts with others previously ignorant of the existence of PWS. This is the definition of PUBLICITY--to make something known to the public. How well the organization succeeds in recognizing our own problems and succeeds in its publicity campaign depends entirely on how each of us succeeds in recognizing our own problems and succeeds in finding their solution.

Delfin J. Beltran, MD

President

WE THANK THE FOLLOWING PERSONS FOR THEIR GENEROUS DONATIONS AND SUPPORT: (July, August)

For Research donors: Alterman Family (9), Combined Federal Fund, Howe (Oberlies, Case, Amacher, Stollberg), Ayotte, Lynch (Battaglia), and Riesman.

For C.I.T.: Bolter (Church of St. Mary), Boyd (2), E. Olson, Dixon, B. Lynch (Palermo), Straight (Hudson), Hutchinson (United Way), Wett (Scanlan, Mast), Womer, Lynch (Pesce), Flick (Giorgi), Castle (Herbst), Jacobs (Pike), Gordon, Maurer, Frontier P.W. Regional Assoc., Blair, Ingalls (Spencer Monday Club), Canova, Miller (Chimples, Jackson), Sunde, Weakly, French, and Berton.

Total Donations for Research Fund: \$2538.48 C.I.T. Fund: \$1752.00

REPRINT AVAILABLE

PWSA has purchased a supply of the Alabama Journal of Medical Sciences reprint, "Prader-Willi Syndrome, Characteristics, Management, and Etiology" by Suzanne B. Cassidy, M.D. Copies are available at \$2.00/each.

SEEKING FUNDS

PWSA has written to the American Legion Auxiliary requesting assistance from their Child Welfare Foundation. If any member knows anyone associated with determining the use of these foundation funds, we can sure use your support.

IMPORTANT FINANCIAL INFORMATION

The 1987 budget approved by the Board of Directors of PWSA reflected an increase in operating expenses as well as an optimistic forecast of increased income from new membership fees and donations for operating expenses. During the first 7 months of our fiscal year, through July 31st, income has been less than anticipated. Even though we have kept expenses to a minimum, PWSA is currently operating at a loss as shown by the figures below.

Savings accumulated over the past few years are being used to pay the monthly deficits but this is money the Board planned to use for new programs and services. As reported at the annual conference in June, balances do exist in the Crisis Center and Research Funds. These are designated funds which cannot be used for operating expenses. Several projects are now planned which will decrease these fund balances.

Contributions in 1987 are needed in order for PWSA to continue funding important new projects for the PW population. Donations from PWSA members, their families and friends, would be appreciated at this time. Let's not allow the growth of our organization to suffer because of lack of funds. (Please mark contribution for fund intended.)

Bud Bush, Treasurer

GENERAL OPERATING STATEMENT

| | <u>12 months, 1986</u> | <u>7 months, 1987</u> |
|---------------|------------------------|-----------------------|
| INCOME | 37,533 | 26,716 |
| EXPENSES | 36,914 | 30,785 |
| PROFIT (LOSS) | 619 | (4,069) |

OUR SOUTH AFRICA MEMBER WRITES:

"Great is the day when your 12 year old son surprises you on a Sunday morning with a breakfast tray, complete with tea and toast, -but when that 12 year old is your PWS child, and he has been so busy with his surprise that he has not had anything himself first, -then that is a major achievement!" She also writes her son is doing well although they are hunting for a better school, and "Keep up your good work."

CONNECTICUT ONE-DAY CONFERENCE

University of CT Health Ctr., Farmington
Saturday, September 26th, 10am - 4 pm
Further information, (203) 679-3342 Cecile

SHOULD PWSA HAVE FUNDRAISERS?

Two recent letters suggested that PWSA have more projects ongoing for fund raisers. The two suggestions were selling packs of cards and putting out cans in stores for donations. Many similar projects have been instigated by chapters for their local needs but not all members belong to chapters.

This subject will be raised at the December board meeting. If you have an opinion, please let us know.

AUSTRALIAN 2nd NATIONAL CONFERENCE

Royal Children's Hospital
Melbourne, October 17-18

ONTARIO 4th ANNUAL CONFERENCE

University of Ottawa Health Sciences Ctr.
September 26-27
For further information (613) 782-8143
days; (613) 731-1627 or 727-5107 evenings.

1987 CONFERENCE PAPERS

Even though taping the conference, transcribing the tapes, and computerizing them is quite expensive, we hate to not make this information available to members who are not able to attend the conference. This year we are offering copies of the tapes, individual transcribed papers or whole sets as follows:

| | |
|--|-------|
| Audio tape of any one presentation..... | 5.00 |
| (Opthamology full paper, Roy Smith, Attorney on Wills (1987), General Meeting, Chapter Reports are available on tape only.) | |
| Complete Set of tapes..... | 30.00 |

Transcribed presentations:

| | |
|---|------|
| A. Suzanne Cassidy's Introductory Remarks..... | .50 |
| B. Services. D.Bolding, SSI Representative..... | .50 |
| C. Obtaining Services, Peggy Brooks-Bertram..... | 1.00 |
| D. Abstracts & Synopsis, Scientific Day Papers..... | 2.50 |
| E. Behavioral Workshop, Introductory Comments..... | 1.00 |
| F. Coping, Bob Hoke, M.D..... | 1.00 |
| G. Group Home Synopsis & Comments..... | .50 |
| H. Medical Questions (Several doctor panel)..... | 1.00 |
| J. Parent's Rights, R.Newbert, Ph.D., Education..... | 1.00 |
| K. Genetics, D.Ledbetter, Ph.D. Lay Explanation..... | 1.00 |
| L. Obesity & Weight, W.Klish, M.D., Sara Phillips, R.D..... | 1.00 |
| M. Wills & Guardianship, Roy Smith, (1986 papers)..... | 2.00 |
| N. Complete Set of above papers..... | 8.00 |

CONFERENCE DISCUSSIONS

Some comments were left unanswered at the conference that we would like to address:

"The Board should be representative of the whole country and of all age groups."

Board members are from Pennsylvania, Minnesota, Georgia, Connecticut, Texas, Iowa, Missouri and South Carolina at the present time, with officers from California, Georgia and Minnesota. If you divided the country into six sections, the only section not represented is the upper West which was represented until the last election.

Age of children represent an age range from 7 yrs. old to 26 years old. Six board members are parents, 3 board members are health professionals, and 3 members are both.

PWSA is having growing pains, there's no doubt about that. It is our opinion the board is facing these growing pains and change in focus. The present board does care about all of the members, they are not trying to meet the own needs for their own section of the country. They are working to represent all of the membership and spend a great deal of time making decisions.

The board will be holding their mid-term board meeting in December. If you have any subjects you would like considered or discussed, please send them to the national office and they will be put on the agenda.

SUMMARY - 2nd ANNUAL PWS SCIENTIFIC
CONFERENCE, June 17, 1987 HOUSTON

by Vanja A. Holm, M.D.

Twenty-five papers were presented, 15 of them on genetic aspects of the syndrome.

Genetics: It is no longer medical news that over 50% of people with the PWS have a deletion of the upper part of the long arm of chromosome 15. Of interest to researchers now is the possibility that, (1) some people who have all the clinical criteria of the syndrome might have other chromosomal abnormalities and (2) some people with the deletion might have atypical clinical findings.

Six possible patients in the first category were presented. However, most of them were "PWS-like", not classical clinical cases. All had abnormalities of chromosome 15 but not the expected deletion. Five patients in the second category were presented. One just lacked the food seeking behavior at age 8 years, two were more severely delayed than the typical person with PWS and had different (but similar for the two) facial features; someone in the audience pointed out that the other two showed similarities to another syndrome located on chromosome 15.

An exciting development in genetics--molecular genetics--is relevant to PWS. Genes are being "mapped" using DNA probes. A group in Boston is investigating the area of chromosome 15 that is deleted in most cases of PWS using such probes. Some interesting findings were presented by Dr. Latt from this group. It is anticipated that the answers to the remaining mysteries of chromosome 15 and PWS eventually will come from such studies.

Two papers on a phenomenon called "sister chromatid exchanges" (geneticists have such an interesting vocabulary!) were presented. They are not increased in the PWS but the papers brought up an interesting discussion on possible environmental inducers of chromosomal abnormalities, another hot subject in genetics and one we probably will hear more about in relationship to PWS in the future.

The physical findings in 5 babies in whom the diagnosis was made in the newborn period by chromosome studies were outlined. The difficulties in counseling parents of young babies were discussed.

Dr. Zellweger presented pictures and findings in 2 brothers and 1 sister with unequivocal PWS (this is the same family previously

mentioned in the GV). A less convincing family from Ireland was presented by Dr. Kouseff. The chromosomes were normal in the affected members of both families.

In a presentation by Dr. Cassidy, she noted that the "official" recurrence risk in PWS of 3-5% is erroneous and based on old empiric data. Instead, in USA and Canada only one family (the one presented) is known with more than one case of PWS, while 1,595 persons are known to PWSA in the same area. This means that the recurrence risk is less than 1/1000. There has been no recurrence of the 15q deletion in any family anywhere up to this time. In children with the translocation/deletion, chromosomes of other family members will continue to need to be investigated as their families have a theoretical recurrence risk which can be ruled out with such family studies.

Endocrinology: The possibility of a steroid metabolic disturbance was suggested by Dr. Chaslow. Hormone precursors called steroid sulfate conjugates showed a peculiar pattern in 7 of 16 patients examined. He speculates this substance might have something to do with appetite.

Growth hormone is typically found to be normal in PWS in spite of the substandard growth of most patients. This was also true in 4 children, who had been treated with first human, later synthetic growth hormone at Stanford. Somatomedin-C (a substance in the blood related to growth) were low, however. The clinical experience by the Stanford group, related by Dr. Lee, was positive with improved growth on and deceleration of growth off the hormone. It is not yet known if final height is improved, however.

Breast development is normal in 44% of adult females with PWS according to Dr. Cassidy and absent in 19%. 70% of adult women never menstruate but can be given hormone therapy. 50% of the males had both testes undescended at birth, and additional 25% had one teste undescended. One of 8 adult males developed a full beard on his own, and additional 4 did so with hormone therapy (which also increases pubic and body hair).

SCIENTIFIC PAPERS, cont.

Other Medical Aspects: A study of hypopigmentation--lighter skin--and hair color--in PWS and its relationship to the nerve fibers from the eyes were reported on and, at a later time, described in detail to the parent meeting.

With proper weight management, life expectancy into the 50's does not seem unrealistic in PWS, a conclusion arrived at after reviewing age of patients known to the PWSA (9% are in the 30-40 age group and 1.2% over 40 years of age).

Dr. Greenswag reported from a questionnaire study of 313 persons with PWS that 15.7% ruminated (brought back food to their mouths and re-chewed it) if she chose a liberal definition for rumination. With a stricter definition, 10.2% were ruminators. Rumination was decreased when "a very strict weight control was lessened somewhat". Dental program to protect the teeth and neutralization of the acid content of the stomach were suggested as remedies.

Rectal bleeding in 2 teenagers with PWS was reported from The Rehabilitation Institute of Pittsburgh. The youngsters were found to have rectal ulcers close to the anus from self-inflicted trauma. Both patients were severe skin pickers.

Behavioral Aspects: It was reported from the same institute that a combined behavior modification/dietary restriction/exercise program in 59 patients had been equally successful in persons with and without the chromosome 15 deletion. The authors noted that an average of 7-800 calories per day was needed for weight loss and that approximately 1000 calories resulted in weight maintenance.

Psychiatric diagnoses in adolescents with PWS was studied in 46 patients by Dr. Whitman. She found compulsive neurosis present or probably present in 13, tension neurosis in 15 and hyperactivity in 1. No psychotic symptoms were recorded. The latter finding arouse a fair amount of discussion as several professionals in the audience had had patients diagnosed with depression.

CALL FOR PAPERS, SUGGESTIONS

One conference ends and we immediately begin preparations for the next one. As you have read, the 10th Annual Conference will be held in Louisville, KY on June 22-25, 1988. The conference attendees are given the opportunity to ask for future topics or presenters. We'd now like to give all of you the same opportunity.

What speakers would you like to hear next year?

What topics would you like addressed? Would you like to request to make a presentation?

The agenda will be formatted in the next few months. Now is your chance to share your requests.

MARYLAND CHAPTER

Marge Wett was able to join a group of parents in the State of Maryland who are interested in forming an official chapter of PWSA.

Subjects discussed included the aims of a chapter in working with children of all ages, promoting the knowledge of PWS in this state, and working to open a group home.

You will be hearing from these organizers soon. If you do not, and are interested in becoming a part of this group, contact Diane Cohen in Waldorf or Lougene Burleigh (301)897-8766.

 * RITA WELCH, for all she has *
 * done for NY & PWS. *
 * THE ALTERMAN FAMILY of *
 * GA for all their continued *
 * interest and action. *

OUR SPECIAL PEOPLE BOX



COURTESY LANGUAGE & BEHAVIOR NEGLECTED IN PWS by Marilyn Bintz

This article is written primarily for parents of young children. My qualifications for **writing**, it are rather tenuous. I am the parent of a 16 year old daughter with PWS, I have spent the past two years of the national PWSA conference working with and observing the youth program, and I have worked for several years as a psychiatric nurse. (Psychiatric nurses spend a great deal of time observing and recording behavior.)

Published literature about PWS mostly deals with the physical characteristics of the syndrome. Very little has been published about behavior. Some authors mention the lack of research on behavior, especially in view of the parental feelings that the behaviors are the major problem. This article does not pretend to be research. It is only an attempt to share some of my observations and to make some suggestions which I hope will help you modify some of your child's behavior in a positive way.

Published literature describes the younger children as friendly, social, and outgoing. Negative changes occur as they grow older. They fail to develop social skills, become stubborn, and have temper outbursts. It is the area of social skills that I wish to address, particularly behaviors that might be called Courtesy Language and Courtesy Behavior. Words such as please, thank you, excuse me, I'm sorry, may I help you, are examples of the first and sharing, taking turns, waiting your turn, waiting in line, and losing are examples of the latter. Many (not all) normal children develop or incorporate these behaviors as they grow older. At both conferences I saw the full range of these behaviors from very good to not at all. At the end of the first day of youth program last year the participants were told to thank the bus driver and their volunteer. Very few did so without a specific reminder. By the end of the third day the improvement was remarkable.

My suggestion is that rather than see these behaviors as talents our children do not **possess** we must see them as a foreign language that must be taught and practiced. Using courtesy language at home with your child and expecting your child to use it with you and other family members would be a first step. Explain when and why you say these words to other people. Give examples such as "What would you say if you stepped on someone's foot? What would you say if you bumped someone and they spilled their milk?" Parents have a bad habit of almost always caring for their child's needs first. Our children need to learn how to be second, third, or last. Find ways to take turns at home. Play games taking turns and point out that they were first last time and it is someone else's turn this time. Practice waiting a turn or waiting in line with reassurance that whatever you are waiting for will not run out before you get there. Make sure they understand the **adjectives** first, before, in front of. Don't assume they do. Practice losing. Devise simple card games or ball games where you can control who wins. When they win congratulate them with a "good job" or "good for you" and when you win expect the same response.

Unfortunately our children do not generalize from one situation to another. Knowing how to say thank you or take turns at home do not automatically transfer to school, church, or playground. Helping them transfer behavior to a new situation should be easier than teaching it there. Role play expected behavior at home before you take your child into an unfamiliar situation. Explain to the best of your ability what it will be like, what will happen, and what will be expected of them. Reviewing expected behavior before you go to church, a movie, the library, **restaurant** or a party may also be helpful.

Interrupting is another behavior that belongs in these categories. I think substantial progress must be made in the other behaviors before you can successfully deal with it. Saying "don't interrupt, it's not polite" will be a waste of time if the child has no other courtesy behavior.

I have written this as though it were some sure-fire method and of course it is not. I think it is worth working on. Anxiety and frustration increase temper outbursts and tearful episodes. Sometimes the difference between tolerable and intolerable is small. A child who cries briefly sometimes is better than one who cries uncontrollably every time. Socially correct behaviors in children frequently receive praise from adults and praise from adults increases self esteem. Finally, I'm not certain changes in behavior cannot be made at any age. Your child is your child forever. Just ask my mother, she is still trying to change some of my behavior.



HANDLING STRESS (from Nat'l Inst. of MH)

You need stress in your life! Does that surprise you? Without stress, life would be dull and unexciting. Stress adds flavor, challenge, opportunity. Too much stress, however, can seriously affect your physical and mental well-being. Make the stress work for you.

Stress is with us all the time. It comes from mental or emotional activity and physical activity. It is unique and personal to each of us. "Taking it easy" can cause stress in some. Too much emotional stress can cause physical illness such as high blood pressure, ulcers, or even heart disease; physical stress from work or exercise is not likely to cause such ailments. The truth is that physical exercise can help you to relax and to handle your mental or emotional stress.

You must learn how your body responds to demands. When stress becomes longer or particularly frustrating, it can become harmful--causing distress. You need to recognize the early signs of distress and do something about it.

Become aware of your own reactions to stressful events. The body responds to stress by going through 3 stages: (1) alarm, (2) resistance, and (3) exhaustion.

If you continue to go through these 3 stages, you can begin to tighten up just at the prospect of it happening. You could add migraine headaches, backaches and insomnia to the above list. When stress does occur, it is important to recognize and deal with it. Try physical activity. You can relieve that "uptight" feeling, turn frowns into smiles. Remember, your body and mind work together. Share your stress. It helps to talk. If it is too serious for friends, turn to professionals. Know your limits. If a problem is beyond our control and cannot be changed at the moment, don't fight the situation. Learn to accept what is--for now--until such time when you can change it.

Take care of yourself. You are special. Get enough rest, eat well. Make time for fun. Play can be just as important to your well-being as work. You need a break--take one, relax, have fun.

Check off your tasks. Taking care of everything at once can be overwhelming. Make a list, do them one at a time, check off until completed. Do the important ones first. Must you always be right? (An important PWS one) Try cooperation instead of confrontation; it's better than fighting and always being "right". A little give and take can reduce the strain. (Unfortunately, for us it has to be more give.)

Avoid self-medication. Although you can use drugs to relieve stress temporarily, drugs do not remove the conditions that caused the stress in the first place. Drugs can create more stress than they take away. The Art of Relaxation. Learn how to relax. Tune out your worries about time, productivity, and "doing right". You will find satisfaction in just being, without striving. Find activities that give you pleasure and that are good for your mental and physical well-being. Forget about always winning. Focus on relaxation, enjoyment, and health. Be good to yourself. (or you won't be good for someone else.)

AUTOPSIES

The autopsy, a vital means of teaching and checking the accuracy of diagnosis, is now done 15% of the time instead of 45%.

Autopsies, checked consistently by one individual, could lead us to valuable information about PWS. Dr. Will Blackburn of the University of So. Alabama in Mobile volunteered a couple of years ago to study tissue. In the sad event of a death of a person with PW, please call the National Office or Dr. Blackburn directly, so arrangements can be made for this very important study.

RESPONSE FROM YOUNGER PARENTS

A letter was directed to younger parents asking for sharing and suggestions. We thank the few parents that did answer. We do hope more members will continue to share ideas and requests for articles.

One parent wrote: I attended the 9th annual PW conference this year. It was my first conference and proved to be very interesting. I am the mother of a 2 yr-old boy who was diagnosed at the age of 3 mo.

The lectures were excellent. Everything from nutrition to estate planning to starting a group home to devising behavior modification techniques were set forth in a clear, understandable manner.

The conference not only gave me facts and figures and things to consider, it also spoke to my heart in seeing and briefly interacting with the children who attended. Certainly this was not the kind of life I had imagined for my son, but it was reassuring to see that the situation can be controlled and life does go on. I made a lot of friends and contacts at this conference. Other parents freely shared information and extended their friendship and answered the million-and-one questions that I had.

My gratitude goes out to those parents who gathered together to form and maintain the PW Association. If not for their efforts, I would not be in the position to anticipate and prepare for the problems ahead. Perhaps, I, too, would be where they must have once been; the limbo of knowing that something was wrong but not knowing exactly what.

I think the most important thing I learned was that each child is an individual. Of course this should be apparent. To me it was not. In reading the literature on this syndrome, I had a mental picture of my son and how he was going to be in the years to come; the obsession with food, the retardation, the tantrums, etc. Added to that were the "horror stories" and the "gloom and doom" that filter through to parents new to the syndrome. I had in mind a life of pure hell in raising my little boy.

I don't think that way anymore. While many of his problems are unavoidable, there are also strengths on which to build. I met one young man with the syndrome

who went to a "normal" high school and participated in the track and swim team. This did not fit into my preconceived notion at all. While this may not be an appropriate goal for all PW children, it opened my eyes to the fact that I had mentally discounted many activities and opportunities which can be open to my son.

Perhaps the comment of one of the mothers sums up my feelings at this point. She said, "It is not easy but look at us, we have survived." May God bless my son and my family, we are going to survive, too.
by Janet Pearson

Another couple wrote that they find the newsletter somewhat depressing at times.

"We would like to see some positive things like: suggestions for behavior modification, more low-calorie recipes, perhaps a section written by the children about their feelings of what ever is on their mind, what to do about public awareness, getting on TV, how to raise money for research, and educational ideas from other schools. We know that each PW child is different and that what works for one does not work for all, but we would like to see the newsletter give parents of young PW children some helpful hints for a more hopeful future."

(These are some good suggestions--can some of you supply some of the things requested? We'll work on them too.)

This same couple wrote: Our son is 3½ and has been walking for 3 mos., but we are thrilled with his progress. He attends a Day Care 3 days a week. He is the only special needs child in the toddler room. The Day Care has been terrific for him; everything has improved such as speech and fine/gross motor skills. The meals are provided there, so I let the staff know what he is allowed to have. They encourage him to eat slowly (which has helped the other children as well by example). The children are rewarded with stamps on their hands rather than food and we have carried this over at home. The Physical Therapist comes to the Day Care once a month to show the staff general PT to do with our son.

He swims twice a week, does have moments of stubbornness and is hard to motivate to do physical things but has come far.

MAJOR CONCERNS

A younger parent wrote that one of her major concerns are low-cal foods and where to find them. She suggested the American Dietetic Association, Family Cookbook, Volume II and Peggy Pipes, Low-Cal Book available from the Texas Chapter as two sources.

She also commented that many new members were not aware of the books that are available from PWSA. (Please let us know if you'd like an order form.)

Some recipes she shared:

Ketchup - 1 Tbs.= 6 calories

46 oz. tomato juice
1/4 cup vinegar
1/8 tsp. each: dry mustard, allspice,
cinnamon, celery seed
1 tsp. onion powder
2 sweet'n-low packets

Combine all except sugar. Simmer 3 hours, til thick, add sugar.

BBQ Sauce - 3 Tbs.= 10 calories

4 Tbs. tomato paste 1 Tbs. onion flakes
1 tsp. worchester sauce 1 tsp. salt
1 tsp. lemon juice 1 minced garlic
1 cup sugar-free cola dash pepper

Combine all, boil, reduce & simmer 10 minutes.

Strawberry Jam 1 Tbs.= 2 calories

2½ cups strawberrries
1½ cups sugar-free strawberry soda
2 pkgs. " " " gelatin
1 tsp. sweet'n-low

Mash berries, add soda, bring to boil, cook 1 minute. Remove from heat, add gelatin, mix, add sugar. Put in hot jars.

She also added: "Help make goals achievable for your PW children. They will walk, talk and communicate when they are capable of doing so, just as any other child. Enjoy them, love them, and discipline them as you would your other children. The most important thing is to take it day by day. All children develop differently!"

Another mother writes: This letter is long overdue! I've been wanting to write since the day I returned from Texas--I had a wonderful time, along with my 3½ yr.old daughter. The conference was the most worthwhile, informative, and a great experience. It was very nice meeting so many couples with younger PW's. The number of people who attended the conference really surprised me.

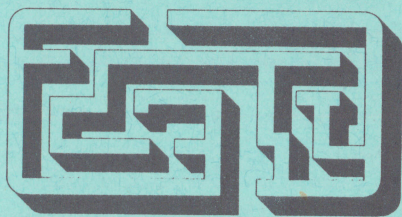
One very important "boost" for me was seeing a good number of PW's with their weight under control. We have our daughter on a modified 800 cal. ADA diet, but most professionals tell us to face the fact that she will be "fat". This always bothered me, but now I can go back to them and say I have met PW's with their weight controlled and we are going to do our best to control ours.

There's a quotation that has been passed around PWSA for years. The doctor says, "you have a child with PW, he/she is going to get fat and die young and there is nothing you can do about it." We felt we really followed up on that quite often but obviously not often enough to have our members know, parents have for years proven these "experts?" wrong.

We are often accused of being negative because we feel a parent has to be knowledgeable regarding the syndrome in order to start a good nutrition diet and exercise program early before the child becomes overweight and really put a great deal of effort into this. Many parents have proven those doctors are wrong, but they have not accomplished this unless they really worked on it. We even have registered dieticians that tell our parents a diet is not necessary because the child is not overweight and early dieting will cause growth problems.

It is very important for parents to find a knowledgeable doctor and dietician that will get their child off to the right start. If these experts cannot be found in your area, then it is up to you, as a parent, to obtain good information on the syndrome and educate them to care for your child properly. Luckily, many professionals are learning but some still need assistance.

UNRAVELING THE SPECIAL EDUCATION MAZE



An Action Guide for Parents

Research Press
Box 3177, Dept. D
Champaign IL 61821
(217) 352-3273

ITEM 2243 \$12.95 + \$2.00
(shipping)

Preface

Many parents are quite literally in the dark about the rights of their handicapped children to a decent and appropriate education. Others may have heard something about the new special education law for all handicapped children, but they believe that their children are too young, too old, too handicapped, or too difficult for the public schools to educate. Yet all children, with or without handicaps, are entitled to a free public education.

Some public school systems, in their indifference to the needs and rights of handicapped children, are like mazes that bewilder parents trying to reach the goal of appropriate and beneficial services for their children. These parents find their efforts leading them to dead ends or through the same paths they have wandered in many times before. They have no way of judging how close or how far they may be from the goal. They need something to guide them.

Public Law 94-142, the Education for All Handicapped Children Act, is the map that can straighten the winding paths of the maze and lead handicapped children to the brighter future which the right educational services can bring. It provides parents with ways to avoid the dead ends and to keep moving forward.

For parents who are now frustrated by or uninformed about the educational system and its obligations to their children, this book offers the chance to learn how to use Public Law 94-142 to get to that more promising future their children deserve and to which they are entitled.

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Can be ordered from Research Press, information above or we have one copy in PWSA Library than can be borrowed.

TIPS BEFORE CHANGING SCHOOLS

1. Your local library or State Department of Education has a list of more than 250 schools that offer exceptional opportunities. You may find one near you.
2. What is the teacher-pupil ratio? Ideal, primary (1-3) 1-20; intermediate any number over 1-25 is too high.
3. Are special needs met? Do they have special education classes, library programs, adaptive physical education, music, speech therapists, psychometrists, school psychologists? These are good questions to ask.
4. You can check the district or individual school's percentile scores on national standardized tests.
5. Do they offer transportation for your child? Many factors can influence the need for special pick up (the inability to walk to bus stop, climb on large bus, etc.)
6. Visit the school you have in mind. Observe the atmosphere, is this a school where your child will thrive? Ask the principal questions.

Another tip, whether you are changing schools or remaining in the same school, attend a class on, "What is an I.E.P.?" (Individualized Educational Plan) Many areas are now holding classes to teach parents their rights in developing these plans.

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