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Newsletter of PRADER-WILLI SYNDROME PARENTS AND FRIENDS

Post Office Box 124
Harvard, Massachusetts 01451
Gene Deterling, Director

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PRADER-WILLI SYNDROME PARENTS AND FRIENDS

Prader-Willi syndrome is a rare birth defect that results in initial hypotonia (lack of muscle tone) and later a compulsive tendency toward obesity as well as other complications. Because of the rarity of the affliction, there is much to be learned about its treatment and perhaps eventual prevention. The non-profit organization, PRADER-WILLI SYNDROME PARENTS AND FRIENDS, has been formed to provide a vehicle of communication for persons who have had experience with the syndrome and those who need to benefit by others' experience.

A one-year membership may be obtained by sending \$5.00 along with your name, address, and telephone number to PRADER-WILLI SYNDROME PARENTS AND FRIENDS, Box 124, Harvard, Massachusetts 01451.

THE BOOK VIEW

Weight Watchers Program Cookbook, by Jean Nidetch, Great Neck, N.Y., Hearthsides Press, Inc., c. 1972, 1973, by Weight Watchers International.

Most of us are probably not members of Weight Watchers International, but how we do watch that weight! Fortunately, we don't have to be members of Weight Watchers in order to buy their cookbook, which is available at bookstores and food outlets.

Imagine feeding your child such luscious foods as cherry cheese cake, "fried" potatoes, seafood fondue, and pumpkin chiffon tartlets. My guess is that you will soon be cooking extra portions of his food for yourself.

The book conveniently lists portion sizes, but calorie counts are not given as the Weight Watchers' system does not involve calorie counting as such. Of special value are the recipes for substitutes for such high calorie foods as sauces, salad dressings, and pie crust.

It appears to me that Weight Watchers has a secret they are not telling openly. The secret lies in watching the food intake more than watching the weight, which is what this book is all about.

Reviewed by Shirley Neason

THE PROFESSIONAL VIEW

Here is a letter received during the past month:

We are about to have our 3rd parents meeting, including parents of ten Prader-Willi syndrome children. The children range from 3 years to 16 years of age. Our meetings are held at the Alta California Regional Center in Sacramento, California.

Thus far, we have discussed the general problems in Prader-Willi, concepts behind dietary treatment, behavioral approaches to control obesity, and various ways of dealing with the behavioral problems of these children. We are fortunate to have the support of the Alta California Regional Center psychologist, Dr. Jeff Miller. Also, at each meeting, the parents share their experiences and concerns.

Your newsletter has been most informative, and our parents have enjoyed the contact with other families' experiences. It was nice to read in the March issue that there is another group in California. Thanks again.

Sincerely,

Andrea E. Netten

Nutrition Consultant, Alta California Regional Center

P. S. While in graduate school at CDMRC, University of Washington, I first heard of Prader-Willi syndrome, but never dreamed the problem was shared by so many.

MESSAGE FROM THE DIRECTOR

For too long now we have heard mainly the negative side of Prader-Willi syndrome. Most of what we have heard and read has portrayed the Prader-Willi citizen as a hopeless, helpless victim of the syndrome. This impression needs to be corrected, and we intend to do our part by presenting the other view—the positive one.

For those of you who have recently been blessed with a new child who happens to have Prader-Willi syndrome, you may consider yourself fortunate if the diagnosis was made before the child reached the age of two. A good share of the difficulties with the syndrome relates to the lack of good dietary habits being developed in the very early formative years. With the aid of a good nutritionist and determined parents, the chances are high that the child will remain a joy rather than growing to be a burden. We have a number of letters to attest to that, and we know from experience with our own son, Curtis, that it is true. Friendly, happy, likeable, fun, sensitive, thoughtful, loving—those are the characteristics of a Prader-Willi child under control. Curtis is now five and weighs 44 pounds. That's three pounds less than he weighed at age three!

We don't have space for them all, but we're including in this newsletter some excerpts from some of our more encouraging letters.

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In our January issue we indicated that we expected our membership would reach 100 by June. We are now happy to report that our membership reached 100 on March 27th. As a result of recent publicity on Prader-Willi syndrome and several new articles regarding our organization, we have been flooded with requests for information and have enjoyed an accelerated membership rate. Although this is a very favorable sign, it has placed an unexpected burden on our home office. Whereas previously we were able to keep up with our correspondence through our voluntary work, we have now been forced to pay for part-time secretarial assistance. Eventually, if our organization is to be successful and fruitful, we will have to hire a full-time secretary. We must also establish our organizational structure and tax exempt status. That will probably require our organization to be incorporated and our legal fees along for this activity will run \$300 to \$500. We cannot, of course, support this activity with our present membership dues. It is only through donations received in memory of Susan Leyshon that we are presently able to carry on.

Although we do not intend to conduct any formal fund raising activity, we must make our membership aware of the need for operating funds. It is our hope that we may be blessed with unsolicited donations, bequests, endowments, or other forms of gifts. We would appreciate hearing from anyone who may have the time and desire to work with some of the charitable foundations to determine our eligibility for funds.

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Our editor, Shirley Neason, along with a group of parents in the Washington State area, has written a draft of a booklet on Prader-Willi syndrome entitled A Very Special Person. We have received it, and are convinced it would be of value to all of us. In order to make it available, however, there will be a publication expense. We would like to work with Shirley to enable this publication to be made available. Once again, we have a funding problem which we are working to resolve. In the meantime, the draft is being reviewed by a number of qualified technical personnel. We will keep you informed on this interesting item.

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Our mid-west members should be pleased to know that a clinic for children with Prader-Willi syndrome has been formed under the direction of Dr. Andree Walczak at the Dysfunctioning Child Center (of) Michael Reese Medical Center, 29th Street and Ellis Avenue, Chicago, Illinois 60616 [tel (312) 791-4233.] A nutritionist, Grayce B. Seidenberg, at the center, may be able to provide further information.

RECIPE: CINNAMON COOKIES

1 slice of white bread, crumbled
1 egg
1/4 teaspoon vanilla
Sugar substitute to equal 4 teaspoons sugar

Mix all ingredients; drop by teaspoonfuls on cookie sheet. Bake at 350° for 10 min. Makes 7-10 cookies. Total calories for all the cookies: 133.

A VIEW OF WHO'S WHO

This is the continuation of the story of Christopher, written by his mother, Ann Watson, of Mansfield, Nottingham, England. This portion of the story was written in 1975.

Christopher was to stay one year at Redgate school before we were told he would not be able to stay there and would have to go to Debdale School. I was very happy whilst Christopher was at Redgate. Everything they could possibly do for him was done. His teacher and headmaster were wonderful.

When we were told Christopher could go to Redgate, I was contacted by the headmaster, Mr. Moodie, who asked us to go look round the school. We were shown everything and made welcome. As we lived close to the school, Mr. Moodie said I could take Christopher to play with the other children at Playtime during the time before he was due to start. Mr. Moodie told me, as he told all parents of his children, that I could go any time to discuss any problems I may have. He made me feel he was more a friend than the headmaster of my son's school.

Then came time for Christopher to be moved to Debdale. Mr. Moodie brought Miss Walker, the Headmistress, to our home to meet me.

Starting at Debdale was so different from Redgate; I had never seen the school or met any of the staff other than the headmistress. I was expected to put Christopher on the special bus, and that was that.

When we went to meet the bus, I asked if I could travel with him. I was reluctantly allowed to do this. When we arrived, I had the feeling I wasn't very welcome. Christopher was put in the kindergarten, and I was introduced to his teacher, who seemed very nice.

Christopher settled in well, and didn't seem any worse for the upheaval of changing schools. He was happy, but didn't make any progress. Zigsaws seem to be the dominant feature at Debdale, and Christopher has never been able to do these. He was 6 1/2 when he started at Debdale, and he has not been able to learn anything much since.

Everything seemed to go well whilst he was in kindergarten. He was stubborn at times, which he always has been, but nothing they couldn't control. During this time we visited the hospital specialist every six months. Now we go once a year, as there is nothing they can do for us. We see the dietician more often now, but getting Christopher's weight down is a real problem.

Whilst he was at Redgate, his weight stabilised, which was a great achievement. However, since he has been at Debdale, his weight has risen alarmingly. I can't understand why, unless it is because he isn't quite as active there. At Redgate he was kept on the move most of the time, and his legs seemed to loosen up quite a lot.

A few months ago I became worried as Christopher seemed to be getting slower and slower. I thought he was going off his legs, so when we saw the specialist in March (1975), I asked if we could see a physiotherapist. This was done, and we now visit the hospital every week for a half hour. Therefore, Christopher only goes to school four days a week, but it is well worth taking him, as his legs are improving slowly. The physiotherapist has been able to get a tricycle for Christopher to use at home, and although he can't guide or pedal it properly, he does get exercise by being pushed round the garden on it.

Christopher was put into another class in September (he was eight in February), and hasn't settled well at all. After he had been in the new class about three weeks, the headmistress sent a message via the lady on the bus to say Christopher had been a naughty boy. When I rang next day to see what had happened, I was told he wouldn't put his slippers on to go into the hall, so he was left in the classroom by himself. Although I am told he could be seen from where the other children were, he did manage to tip over a fish tank and various other items. I feel with more understanding this could have been avoided. When Christopher is upset he will do these things, but it is very rare.

He has been very awkward in school and on and off at home. As this trouble was upsetting the school, I took Christopher to see the doctor. He listened to my problems, then said he could give him a tranquilliser to help him over this period, as he was obviously under great stress.

When Christopher started at Debdale, he was given a medical after two weeks, and the headmistress had suggested he be given the drug largactil, as he was overactive. Christopher has always been far from active, and his movements are very slow. When I said this, she said he walks around and talks a lot. That to me was far from active, as for a year whilst he was at Redgate he was encouraged to walk around as much as possible. I was asked to see the doctor about giving Christopher this drug, which I did. He wasn't agreeable at that time to him having it, and neither

was I. I am not happy about having to give him the Valium, but I realise he needs it for a while. I shall stop giving it to him as soon as possible. I realise with having so many handicapped children in each class, it is very difficult for the teachers involved, and I do believe the teacher Christopher is with at present is doing her best to help him with his problems.

However, I do feel closer contact with parents and school would help all concerned. I do now have a book sent from school once a fortnight, in which the teacher writes anything she wants to tell me, and vice versa. This is a step in the right direction. Putting on paper my feelings is rather difficult, but with handicapped children I feel there should be closer contact with parents and school. Our children can't tell us what they have done all day, so we can't follow up on the work they are doing. E.g., when Christopher was in kindergarten he was taught to put on his coat by his very patient teacher. I didn't know this, so therefore, he wouldn't try for me. I had tried without success to teach him, so he was putting his coat on at school and not at home. It was only by chance the teacher mentioned how pleased she was that he could put his own coat on. Then I was able to carry out her good work, and she taught me the right way to teach Christopher to do this.

Looking back since Christopher started school at 5 1/2, he hasn't visibly learnt anything. Before he went to school I taught him all the usual nursery rhymes, but have been trying for months to teach him another one, but it is very hard. My feeling is that he has gone as far as he can with learning, or we just haven't found anything to hold his interest long enough to learn anything.

I have been trying with flash cards to teach Christopher a few words. He likes the Ladybird Book about Peter and Jane, and I used this at the suggestion of a friend as a basis for my words, but it wasn't too successful. He seemed to recognise the Peter and Jane, but I think it was more luck than judgment. We then made cards for various items in the house; e.g., door, chair, window, television. We made it a game, but he soon tired of it, so I have put them away to try again at a later date.

The headmistress is talking about seeing a psychologist who has been appointed to Special Education, but I can't see what they can do. When Christopher is awkward, nothing I do will stop it, and I think I have tried everything possible. I found it best to ignore him as much as possible, and he seems to come out of it a lot faster. Apart from being a mother, I know I am not qualified from books, but I have eight years of experience by trial and error.

Through the parent of another handicapped child I was told about a group called "In Touch," which is run by a wonderful woman called Ann Worthington from Sale in Cheshire. She sends out a newsletter three times a year, giving all kinds of information. There are about 700 families with all kinds of handicaps on her list.

Whilst Christopher was at Redgate, his teacher told me about another boy who lives at Hucknall with the same condition as Christopher. She gave me her address, and I wrote to see if his mother would like to write to me. Better than this, as soon as she got my letter, she rang me. That was the beginning of a marvelous friendship. We tell each other all our troubles. We know that when we say we understand, we really do, as we have similar experiences. We visit each other for tea regularly, and in school holidays we spend a day at each others' homes.

Some friends in America sent me a newspaper article about Prader-Willi children and its symptoms. Also they have put me in touch with a group called THE GATHERED VIEW, a newsletter for PRADER-WILLI SYNDROME PARENTS AND FRIENDS.

RECIPE: RICE PANCAKE

1 egg
1/3 cup cooked rice
1/8 teaspoon flavoring or spice
Dash powdered sugar substitute
Dash salt

Beat egg with fork. Add rice and other ingredients and stir. Spray griddle or frying pan with no-calorie vegetable coating and pre-heat to 350°. Bake pancake.

Exchanges: One bread, one meat.

THE GATHERED EXCHANGE

Excerpts From Our Special Audience:

From M.S., Warwick, R.I.:

Peter is a special boy, loved by everyone who knows him. Because he has overcome so many handicaps, he has become a little story all his own . . . After ten years of diet pills and hospital stays to lose weight, only to see it pile up again, a miracle--so it seemed--happened. A doctor developed a protein-sparing diet. Peter, with a few other Prader-Wills was taken in for a try at the impossible. Some of the children have not been able to tolerate the strict diet of only three oz. of meat or fish three times a day, with only black coffee or diet soda. Peter once again became a wonder to everyone around him. He prepared his own meals and never cheated. He has lost a hundred and forty pounds in less than a year. This may not sound like much of a feat to some, but Peter is a retarded child with the supposed mentality of eight and the compassion and understanding of an old man. Peter--like so many special children--radiates affection for people. When he shakes your hand and looks in your eyes, you see a warm-hearted, tender boy. Peter has received so much help and love from everyone who knows him, that at the ripe old age of eighteen with many afflictions behind him, he shows a deep caring and sensitivity to others that I wish my other children had more of. You see, I'm very proud to say, Peter is my son.

From K.W., Boyne City, Michigan:

I have a son who was diagnosed as Prader-Willi at birth. He is now 5 1/2 and through the help of our Intermediate school district has made great strides in combating his handicaps Since last April (1975) he has lost 21 lbs., now is attending regular school and doing quite well. Can jump, turn somersaults, and walk a mile without exertion.

From M.R., Felton, California:

My son was diagnosed when he was 12--he is now 14. His appetite has been a constant battle in the past, but shows signs of decreasing or coming under control in the past year or so. Puberty has also seemed to help. He is now 5'6" and 146 lbs., which is the best ratio he's ever been.

Two members have written requesting to correspond with other parents. If you would like to respond to either of them, please send your letter directly to them at the address given.

Am interesting to know if there are other members from New York State. Also would like to hear from any parents anywhere who have adult children with this syndrome. Our boy, Billy, has been working in a center for the handicapped. He has become bored and frustrated from the many rules and repetitive, unimaginative jobs offered. We are now in the process of trying to set up a farm type setting for the handicapped in this area, where they could have a variety of activities. A few we have thought of is a woodworking shop, a greenhouse, small animals--a dog, cat, chickens, ducks, etc., for them to care for which could develop into a children's farmyard-- a ceramic shop, since we have molds and a large kiln which we already work with a home. This is still in the planning stage, but we feel there is a definite need for something like this in our area.

Ruby Stephens, 8 Floral Ave., Cortland, New York 13045

What we would like to know is if there are any parents in the Minneapolis or St. Paul, Minn., area we could get in contact with. My husband and I would appreciate any information we can be given.

Mr. and Mrs. George J. Maas, 6880 Channel Road, Fridley, Minn. 55432

Visiting Seattle?

Speaking of parents communicating with one another, if you are traveling from a distance and need to consult with the University of Washington for consultation, and will need to

stay overnight, please contact THE GATHERED VIEW. Some parents in this area have expressed a willingness to share their homes with other parents of children with Prader-Willi syndrome who need overnight accommodations. In addition to cutting your costs, it will give you the opportunity to become acquainted with another family with problems similar to yours. If you are coming from out of town not needing overnight accommodations, but would still like to meet other parents, let us know that. Often we can find another parent who would be willing to meet you at CDMRC, if he or she can work his schedule to match your visit.

An answer on force-feeding and left-side weakness:

Our child was force-fed for three months and did have a more pronounced weakness on his left side. The doctor pinned his nightgown up on this side to be sure it would have good circulation.

He never cried as a baby until three months old, then he cried for three hours straight. He didn't cry again until he was a year and a half old. We had to set the alarm clock to feed him as he would open his eyes when he was hungry, but not cry.

Ruby Stephens

An answer on the habit of picking at sores:

Our son, 24, still has this habit, though not as bad as when he was younger. It is real important to keep the open area clean and antiseptic on them. Our boy developed a staph infection three years ago which the doctor felt possibly came from one of his open sores. Bites in the summer was one of his biggest problems. Washing or soaking the affected area in soda water and then dusting with corn starch helps relieve the itching.

Ruby Stephens

THE GATHERED VIEW
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