THE GATHERED VIEW

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Federal Way, Washington 98003

Newsletter of PRADER-WILLI SNYDROME ASSOCIATION

Gene Deterling, President

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PRESIDENT'S MESSAGE

We are now three years old. It was in July, 1975, that the first issue of THE GATHERED VIEW was released to the world. There were only ten of us, however, at that time to receive the first issue that month. It wasn't long, though, before the word got out about our organization and by the end of 1975, seventy-five of us had joined hands in this venture of sharing and helping each other. We are pleased with our first three years of progress, and we expect to continue to improve our programs as we grow. One only needs to compare our first copy of THE GATHERED VIEW with our latest issue to note how far we've come in our three-year existence. Now with over 320 of us working together, we have reason to believe we will be even prouder of our next three years.

One current event of which we are particularly proud is the release of the Parents Handbook. It has taken considerably longer to produce than anticipated, but I believe all those who receive it will feel it was well worth the wait. The responses we have received so far have been very positive. I personally feel it is an excellent publication and highly recommend that all members request a copy of the handbook from Shirley Neason at our GATHERED VIEW office in Washington State. I also wish to publicly commend Shirley Neason for her superb accomplishment in putting this book together.

I am also proud to announce that I was recently presented the Honeywell Community Service Award for my efforts associated with the foundation and operation of the Prader-Willi Syndrome Association. In addition to receiving a plaque, a Community Service Award lapel pin, and a gold-plated photo prism, Honeywell has donated $500 to the organization of my choice which, needless to say, is the Prader-Willi Syndrome Association. I owe particular credit to so many of you who have made this accomplishment possible.

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On June 10th, our annual Board of Directors Meeting was held in San Francisco. Our primary task at this meeting was to recommend, review, and approve business matters related to the operation of the organization. Of significance to all is the plan we have established for next year's meeting. In order to allow our entire membership to more fully participate in the activities of the association and to provide an opportunity for direct communication

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PRESIDENT'S MESSAGE, Continued

with each other and some of the top professional people in the world, we are planning a two-day session that will include speakers, workshops, discussions, and other activities that should be of value to both parents and professionals. The meeting will be held in Minneapolis on Friday and Saturday, June 29th and 30th. We will, of course, advise you of the details as they are developed. It's not too early, however, to start thinking about this event and setting aside some time to attend. We realize that the distance will be a problem for many, but we suggest that at least one representative of your local group (if one exists) be encouraged to attend. For those who must travel, a portion of your expenses should be deductible from your Federal Income Tax.

We would appreciate hearing from you soon about your interest in this session since we intend to plan it to meet your needs and interests.

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The detailed minutes of the Board of Directors Meeting are published on the final pages of this newsletter.

THE MEDIA VIEW

It's Here!

The booklet, "Prader-Willi Syndrome: A Handbook for Parents", is here! Those who have already ordered should have received your copies by now. (Orders mailed after June 20 should allow extra time to receive theirs, as the editor will be on vacation until July 20.)

Incidentally, we added the cover picture to the booklet last and were unable to credit the artist in the book, so we want to recognize him. He is Gordon Umino of Security Graphics in Everett, Washington. Gordon is a special person in his community because he hires developmentally handicapped people.

The booklet cost more than we had anticipated, and this additional expense, along with the recent increase in postage has necessitated an increase in the price of the booklet. At the Board of Directors meeting it was decided to permit each member to buy one copy at the price of $2.00. The price for nonmembers and for additional copies to members will be $3.50. Please send orders to THE GATHERED VIEW, 147 South 294th Place, Federal Way, WA 98003.

Now that the booklet has been published, we would like to begin collecting material for the revision that will undoubtedly be needed in a few years. Please send your ideas and comments. The information in the booklet was based on the experience of a few parents; it may be that you have additional information or disagreements that will benefit others. Feel free to send your ideas for THE GATHERED EXCHANGE, and give other parents the opportunity to discuss the ideas. This is the best way for the newsletter to function the way its name implies: to gather the views of many parents and friends to exchange with others who are trying to help those with Prader-Willi syndrome.

Another Article About Prader-Willi Syndrome:

An article, "Our Experience With Prader-Willi Syndrome," written by the editor of THE GATHERED VIEW, appears in the July issue of Home Life, a magazine with national circulation. This is a Southern Baptist publication, and if you would like a copy, try contacting a Southern Baptist church in your community and ask them for one. Most churches distribute them free, but if some don't, I'm sure a member family would be willing to save their copy for you.

CALIFORNIA SCHOOL HAS "SPECIAL LUNCH CLUB" FOR DIETERS

At the Board of Directors meeting, Andrea Netten Sechrist, R.D., presented a slide talk about a unique club in a school for trainable and educable retarded in California. A teacher, with Ms. Sechrist's help, formed the club for students, among them those with Prader-Willi syndrome, who were overweight. The club has its own T-shirt, and the children are very proud of themselves, showing a vast improvement in self-image as a result of the club.

Each day at lunch time the kids, with their sponsor, go to the school kitchen and prepare their own lunch. They have made up a scrapbook showing the caloric values of different foods. Menus are planned a week in advance and sent home so parents can work them into their menu plans.

The teacher-sponsor of the club became interested when she realized how devastating it was for these children with severe food problems to be so different from other children. Now club members are permitted to compare their lunches with the regular lunches and see that, although the calorie value of their food is much lower, they are actually getting a larger volume of food. They now feel special, rather than different.

The refrigerator in the school kitchen is not kept locked, but there has been very little stealing. Stealing or "snitching" is punished by denial of diet soda or D-zerta dessert. Punishment usually corrects the behavior for a period of at least three months.

Ms. Sechrist is planning to prepare a tape to go with her slides, and will have the presentation available for loan to other groups when it is completed. We will let you know how to order it when it becomes available.

In the meantime, we have several copies on hand of the April issue of "Alta Action", newsletter of the Alta California Regional Center for the Developmentally Disabled. This issue carries and article and picture of the program. If you would like a copy to share with your child's teacher, send a stamped, self-addressed envelope to THE GATHERED VIEW with your request.

GATHERED REPORTS

Cleveland, Ohio

I attended the meeting in Cleveland, Ohio, on May 6th with Dr. Ruth P. Owens at Rainbow Babies & Childrens Hospital. One of the many ideas discussed was the need for the association to contact CBS and 60 Minutes about a topic on Prader-Willi syndrome to help inform the nation about the syndrome.

A parent in the area is willing to be interviewed by the local newspaper in an effort to help other parents or educators identify more children with the syndrome. 60 Minutes is always asking for topics and this would be extremely beneficial.

Reported by Sondra Blackaby

Sacramento, California

There was a meeting at Alta California Regional Medical Center in Sacramento on April 26, 1978. Art Grix, M.D., Carl Paternite, Ph. D., and Polly Hand opened the meeting.

They are beginning a new evaluation program. It will include medical, psychological, educational, social, and behavioral aspects of development.

Reported by Judy Schultz

MARK YOUR CALENDAR NOW !!

Next year, instead of just a board of directors meeting, there will be a general membership meeting. It will be held in Minneapolis, Minnesota, on June 29-30, 1979. Exciting plans are afoot, so include a trip to Minneapolis in your vacation plans.

The Minneapolis parents group will be hosting the convention, which will include speakers, panel discussions, and times for parents and others to just get together and talk about experiences and exchange ideas.

We hope all of you can come, but if it is not possible for all to attend from a given area, try to send a representative. Be prepared to present your nominations for board members and your ideas for discussion and action. Also plan to have a future meeting in your area. We would like to have the meeting in a different part of the country each year so that as many people as possible can attend.

MENUS FOR A MEASURED DIET

Each menu and each recipe is for one serving. Calorie count is listed after each food.

800-calorie-per-day Menu

Breakfast:

1 medium egg	72
¼ cantaloupe	39.8
8 ounces nonfat milk	80

Lunch:

½ cup cottage cheese	96
1 cup broccoli	40
4 or 5 carrot sticks	23
1 stalk celery	15
½ cup cucumber	8
3 apr cots	55

Dinne :

Shrimp salad:

2 ounces boiled shrimp	128
1/8 head lettuce	9
¼ cup sliced or grated carrot	11
2 sliced radishes	5
¼ small tomato	5
¼ cup cucumber	5
1/3 cup corn	55
¼ cup zucchini	11
8 ounces nonfat milk	80
½ cup diet gelatin dessert	8

For 1000 calories, add

Breakfast:

1 slice of toast with ½ teaspoon margarine	100

Lunch:

8 ounces nonfat milk	80

For 1200 Calories, add all of the above, plus

Lunch:

1 ounce cheese

Dinner:

1 ounce shrimp	64

Zero Salad Dressing:

2 Tablespoons lemon juice
1 Tablespoon finely chopped onion
½ cup tomato juice
Salt, pepper, and other seasonings to taste

Combine ingredients in a jar with a tight fitting lid. Shake well before using. Add parsley, green pepper, horseradish, or mustard, if desired.

THE GATHERED EXCHANGE

New Format

Beginning this issue we are using a new format for THE GATHERED EXCHANGE. Rather than introductory comments for each item, we are using headings. We feel this will make it easier for readers to find items when they are looking for information on a given subject in back issues.

Sympathy Extended

I extend my sympathy to the Mears at the loss of their son.

D.B., Iowa

Picking and Scratching

One thing I found really helpful with the eczema-like places on my child's skin is Kennilog, which is a synthetic corticosteriod. A few applications of very tiny amounts works wonders. She doesn't pick at them so badly, either, since we've discovered this.

A.P., Texas

Toys

Tie an empty thread spool onto the end of the string on a pull toy for your young child. This will make a handle that will be easier for him to hold on to as he pulls.

Pain Sensitivity

K. is two and a half and I've always felt that he doesn't feel pain; he seldom cries when he does get bumped. One might panic and have the appendix removed, but it just happened that Dr. Z's nurse called today, and I mentioned this to him. He said not to worry; there is some medicine which he would explain at our visit in the fall.

Speech Development

I was aware that speech would be a problem and K. says a few words we can understand, and is very quiet. He is on a Project Child program for two years now, and speech is something we always work on, but is very very slow in coming.

Diet Control

At two and a half hunger is still not a problem. He gets fruit, meat, vitamins, and breads, but not additional sugar added. He is short for his age and looks like a well-filled out baby. Seems to me his poor muscle tone accounts for his chubby appearance.

Hypogenitalism

I'd appreciate any information. My boy is eight and a half years old. We are planning on more hormone shots and possible surgery on the undescended testes this summer. Has anyone had experience with this?

Diagnosis

The University of Washington is keeping on file the names of physicians who have successfully diagnosed Prader-Willi syndrome. If the name of the physician who diagnosed your child is not on file, please send it to THE GATHERED VIEW, and we will see that the University gets it.

PRELIMINARY REPORT ON QUESTIONNAIRE

At the meeting of the Board of Directors on June 10, Dr. Vanja Holm of the Child Development and Mental Retardation Center of the University of Washington, gave a preliminary report on the results of the questionnaire sent to parents and others involved with people with Prader-Willi syndrome.

A total of ninety-eight responses were received. Of these, eighty-five have been analyzed to date. Those that analysis revealed that the diagnoses of Prader-Willi syndrome was incorrect or doubful were rejected. As yet, the information has not been put through the computer, so the calculations are subject to correction.

Most of the replies came from parents. The youngest person involved was one year old, and the oldest was thirty. Four were less than five years old and twenty-nine were over sixteen. There were forty-two males and thirty-three females. The study brought out no "clusters" of incidence according to date or place of birth.

All but six of the subjects had an abnormal cry in infancy. Most had a low birth weight, but were not premature. Two were premature, and one was postmature. The time during which infants experienced feeding problems ranged from one month to five years, with the average being one to one and a half years.

Among the subjects of the responses, six had normal intelligence; eighteen were borderline retarded, twenty-two were mildly retarded, and nine were in the high moderate range. Academic achievement did not reflect intelligence level, as the average grade level of achievement of those over sixteen years of age was 2.6. Reading level was much higher than overall academic level.

Most of the subjects lived at home or combined home living with residential living. In response to questions concerning age-appropriate self-help skills, forty-six were listed as having appropriate feeding skills; thirty-seven with appropriate dressing skills; twenty-nine as having appropriate independence in the community; and nine as having appropriate time and money concepts. Among the most frequently mentioned strong skills were puzzles, music, and handicrafts.

A number of medical questions listed on the questionnaire brought these responses:

ne half had abnormal saliva, usually sticky or foamy.

ll had small hands and feet.

Twenty-two had frequent diarrhea and stomach upsets, with nineteen out of the twenty-two listed as having diarrhea only. Many commented that the child never vomited.

All males had abnormal genitals. Of the adult females, six had menstruated but started late, one started at thirteen but did not have regular periods, and six had never menstruated. Four developed early pubic hair.

Fourteen reported no skin picking; fifty-six reported a skin-picking problem.

Fifteen reported decreased sensitivity to pain; fifty-three no decreased sensitivity.

Seven had diabetes; three had high blood pressure; and two were deceased.

All reported behavior problems relative to food, unless controlled.

A CRAFT SUGGESTION

Make a vase. Stick random size pieces of masking tape over the outside of a glass jar or bottle. Paint with shoe polish or felt markers. Shellac.

A VIEW OF WHO'S WHO

The WHO'S WHO column is the part of our newsletter for which we get the most material from readers. As a result, we get behind in printing the stories. This month we are devoting more space to the column to catch up on a few of the stories in our files.

A story of a girl with Prader-Willi syndrome:

C. was born on Januray 18, 1971. She weighed four pounds seven ounces at birth and came into the world Frank breech. I felt no life or movement while I carried her, and was worried as to why not. She was my fifth baby, and I knew this was not normal. I worried that perhaps she didn't have arms and legs.

Seeing her at birth I soon realized something was wrong, but no one could tell me what. She was put immediately into an incubator. She was a real floppy baby, so the doctor who took care of her told us. She could not suck, so was tube fed and left in the incubator for six to seven weeks. There she was content to sleep. She didn't move arms or legs unless moved by the doctor or nurse.

When she was released from the hospital she could only take one ounce of milk at each feeding; there were times when I had to put it in her throat with a dropper.

She could not hold her head up for a long time, and was three years old before she walked, During this time I had visited hospital specialists and more doctors, but no one could tell me what was her problem. We were told by one specialist that she could be retarded.

We were thankful that her eating habits had improved, but, oh dear, they had improved so much she had become a real little butterball. Then the diets started along with headaches and heartaches of the diet routine. At the end of the diet period she had gained ten pounds. The doctors put her in the hospital on a strict diet, and as usual, she gained there as well.

Her pediatrician suggested we take her to a specialist in Halifax. There a Dr. Richard Goldbloom, along with other doctors, confirmed that she had Prader-Willi syndrome.

We brought her home, and the nightmare started. She stole cream and milk from the neighbors' porch after the milkman left it. We had to hide everything and it seemed a real fight to keep her and food apart. The other members of the family suffered so much when the outside children in the village called her "pig" and other nasty names. Her sisters and brothers would fight and beat up on the neighbor children who teased her. Each meal we had as a family would end in all of us crying and it near ruined our family life. The only hope we had to cling to was the Lord, and some day someone would help us.

By the time C. was six years old, she weighed 131 pounds and was unable to get up if she fell down. We had to do everything for her; she was fast becoming helpless. So once again we returend to Halifax and the doctors suggested they put her in the hospital on a real strict diet. They soon found out this would not work.

They had to do something real fast or C. would be a bed patient and not able to return to her home and family. The doctors decided to do an operation. This was the only hope, if it worked and she lived through the operation. In November, 1976, they did a bypass operation. She did pull through and spent a

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A VIEW OF WHO'S WHO, Continued

week in the intensive care unit. It was a rough decision and for weeks we wondered if it would work for her.

It did work, and after nearly two months, C. was able to come home to us. She was put on a 500-calorie diet and vitamin supplement. She no longer craved large amounts of food and is losing weight steadily. In November she weighed 131 pounds; nine months later she weighed seventy-five pounds, and could run around and play like the other members of her family. Her diet later was increased to 700-800 calories per day.

She wears glasses and there are still other complications to keep under control. We take her to see the pediatrician once a week, but in general she is a happy, warm, loving, little girl full of life and love. Each night we as a family thank God for our very special little girl.

From M.P.:

I am most interested in your organization, having worked with a 35-year-old retarded man with Prader-Willi syndrome. Due to his age, Prader-Willi was not diagnosed, and his parents were led to believe that his overeating was of an "emotional" nature.

My staff and I developed a weight control program for him based on behavior modification. To my surprise, having read the literature on controlling overeating in Prader-Willi, R. has lost eight pounds in six weeks of our program and is doing well in developing better eating habits. His parents are thrilled.

From C.L.:

At present my little boy is going to the Center for Developmental and Learning Disorders at the University of Alabama in Birmingham, and he is doing very well.

From B.T.:

J. has been on a very strict diet since Thanksgiving (1975) and has lost 47 pounds. But I know there is much more we could be doing for him.

From another parent:

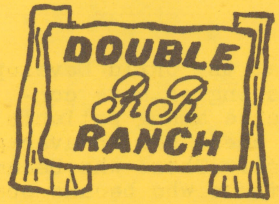
We have a son who has been diagnosed as having the Prader-Willi syndrome. He is seven years old, 48" tall, and has weighed 70 pounds for three years.

He goes to special education classes in the public school system. He can write his first name without any problem; however, with such a long last name, he has difficulty with that. We are working on counting to 100. He still gets mixed up when he gets to the 10s. He knows some of his letter sounds. We are working on that and also simple adding. He has improved with his speech, but still has a lot to improve. He can swim and can ride a two-wheeler with training wheels. He can dress himself completely except for tying his shoes.

This story is about a boy who lives in the Eastern United States:

P. has come a long way in school this year. He is in an ungraded class. He has improved in his social behavior, classroom skills, and participates in special gym classes much better than before. He still doesn't put much energy into it, but he attempts.

We feel fortunate that he is the only one we have at home. He was born eighteen years after our youngest. He has three brothers. When our three grandsons are here at mealtime, our sympathy goes out to parents with a Prader-Willi and other small ones too.



Double R R Ranch, a residence and summer camp designed to meet the needs of children and youth with Prader-Willi syndrome, has acquired a new facility for the summer program. A six and a half acre camp with cabins will house summer campers, and the facility used last year for the summer camp will become a year-round residential unit. The residential unit has four residents registered, and all are expected to be living there by the end of July.

Virginia Wright and Rose Jones, counselors at Double R R Ranch last summer, will alternate at the camp unit this summer. They are full time counselors at WISER Acres, another group home for young people with Prader-Willi syndrome, but are sharing their time and experience so that the new counselors can become better acquainted with the problems of the syndrome and methods of dealing with those problems.

THE PROFESSIONAL VIEW

Nancy Couhig, R.D., a nutritionist at the Child Development and Mental Retardation Center of the University of Washington, has developed some low-calorie recipes to pass along to parents. The recipes are family-tested, as Nancy has been testing them on her own family.

YOGURT DRESSING

1 cup yogurt
2 tablespoons imitation bacon bits
1 teaspoon powdered sugar substitute
1 teaspoon dill pickle juice or
¼ teaspoon dill weed
1 teaspoon garlic powder.

Mix all ingredients together.
200 calories per cup.
12 calories per tablespoon.

SPRING DIP

1 cup lowfat cottage cheese
⅓ cup chopped parsley
1½ teaspoons celery salt.

Blend ingredients in blender or electric mixer.
254 calories per cup.
21 calories per tablespoon.
Can be used on baked potato.
Keeps about three days in refrigerator.

LIGHT AND LOW CHICKEN CACCIATORE

4 chicken breasts, cut in half
1 medium onion, sliced
1 16-ounce can stewed tomatoes
1 green pepper, seeded and chopped
1 2½-ounce can sliced mushrooms
½ teaspoon salt
¼ teaspoon pepper
¼ teaspoon garlic powder
¼ teaspoon Italian seasoning

Spray large skillet with non-stick coating. Brown chicken. Add onions and tomatoes. Cover and cook 30 minutes, stirring occasionally. Add green pepper; cook 20 minutes. Add mushrooms and seasoning; cook 5 minutes.

Calories per recipe: 927
Calories per whole chicken breast: 386
Calories per half chicken breast : 184

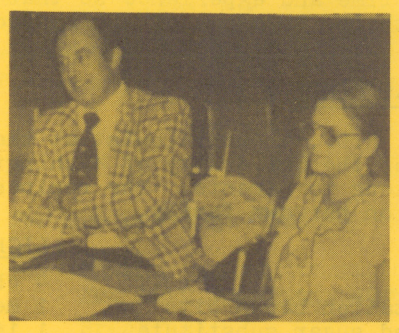
GATHERED NEWS

A new book that at first glance might attract the attention of parents of children with dietary problems is entitled Snackers: Kick the Junk Food Habit. A letter to the Seattle Times signed by nutritionists at the University of Washington warned, however, that though the book claims to offer "alternatives" to sugary snacks, the author defines "sugar" as being refined white sugar only. Most of the book's recipes contain sugar in other forms such as honey, molasses, or maple sugar. Among the signers of the letter were Peggy Pipes, M.P.H., and Nancy Couhig, R.D.

NEW DISCOVERY CONCERNING INTELLIGENCE

Based on evaluation of their patients, staff members at the Child Development and Mental Retardation Center of the University of Washington have concluded that obesity has a direct correlation with intelligence among patients with Prader-Willi syndrome. Patients who had never become obese had an average I.Q. twenty points higher than patients who did become obese. Those who became obese lost I.Q. points as their weight went up. However, those who became obese then later lost weight did not regain I.Q. points as they lost weight, although they did receive other benefits from losing weight.

THE VIEW IN SAN FRANCISCO



Photos were taken at the PRADER-WILLI SYNDROME ASSOCIATION Board of Directors meeting in San Francisco on June 10. Since you editor is strictly an amateur photographer (I've probably taken no more than a total of five rolls of film in my life) not all the pictures turned out, so all of the directors present are not pictured. Those pictured are, left to right, Peggy Pipes, M.P.H., Dr. Vanja Holm, Eugene Deterling, Judy Schultz, and Dr. Delfin J. Beltran.

MINUTES OF THE PRADER-WILLI SYNDROME ASSOCIATION
Board of Directors Meeting - June 10, 1978

The following Board members were present:

D. Beltran, G. Deterling, B. Hall, V. Holm, S. Neason, A. Sechrist, P. Pipes, and J. Schultz.

Dr. Beltran, Board Chairman, opened the meeting with some suggestions for the format and content of this and future meetings. He proposed that time be set aside at this meeting to plan for a meeting next year that would involve more of the general membership of the organization.

Dr. Beltran then commented that since much of the meeting would center on discussion of financing of the organization, he felt it necessary to caution the Board about the dangers of considering federally funded programs for non-

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MINUTES, Continued

profit organizations. He advised that with the restrictions and controls associated with federally funded programs, any such funds obtained by the Prader-Willi Syndrome Association might be too difficult to manage. A discussion took place regarding funds from non-federal sources such as the major foundations and large charitable organizations. Dr. Hall agreed to investigate the possibility of obtaining funds from one of these latter agencies to be used to conduct a centralized annual meeting/workshop next year.

The meeting was then turned over to Gene Deterling for the President's report. He began by covering 20 major accomplishments since last year's meeting. Special praise was given to Shirley Neason for her publication of the Handbook for Parents. The financial status/projections for the years 1975 through 1979 was then presented. It showed the growth of membership rising from 55 at the end of 1975 to a projected 415 at the end of 1979. The proposed 1978 and 1979 budgets showed the working capital remaining about the same as in 1977 as a result of increased anticipated expenses. The detailed 1978 and 1979 operating expense budgets were then reviewed. Mr. Deterling then emphasized the need to establish a salary structure if the association intends to have any degree of permanence. He emphasized that the task of running the organization and producing THE GATHERED VIEW is now beyond that which can be expected of purely voluntary assistants. Although the proposed salaries for the secretary and editor of the newsletter were only token salaries during 1978 and 1979, it was pointed out that we would have at least established the structure from which the administrative portion of the organization can grow. The proposed secretary's salary was $1,000 in 1978 and $2,000 in 1979. The proposed editor's salary was $500, increasing to $1,000 in 1979. Mr. Deterling also discussed the need to purchase a used copy machine. He indicated that the funds received in his name from Honeywell would cover the purchase of such equipment. Dr. Beltran stated he had a copy machine that the organization could use, but Mr. Deterling felt that the mailing of material to be copied would be too significant an inconvenience. It was agreed to give it a try, however. The Board gave approval for the purchase of the equipment and for the payment of the proposed salaries to the secretary and editor.

The Board then discussed what price should be charged for the Handbook for Parents. Shirley Neason stated that the total cost of publication had exceeded $1,200. It was finally agreed by the Board that it would be necessary, in order to cover our publication costs, to request a donation of $2 from each member on ordering their first copy, and $3.50 per copy thereafter. Copies to institutions and non-members will be $3.50. Special prices may be applied for quantity orders when approved by the President. Shirley Neason was asked to promote the handbook by sending announcements to the various medical journals and other applicable periodicals.

The overall 1978 and 1979 budgets were then approved by the Board of Directors. It was agreed, however, that the organization must build up its working capital if we are to be able to support our planned growth. G. Deterling was asked to open a savings account in which the working capital can be maintained.

Plans for next year's meeting were then discussed at length. There was concurrence that the next meeting should be held in a more centralized area convenient to all of the membership. It was decided that the next meeting would be a two-day meeting which would allow a greater particpation by the overall membership. G. Deterling volunteered to have the meeting in Minneapolis and to head up a committee to plan for it. Dr. Hall suggested that we should invite Dr. Prader to attend our meeting. All members were essentially

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MINUTES, Continued

in agreement with the plan for next year's meeting and set the date for June 29th and 30th.

The election of new Board members was then held. Since there was only one new candidate, and there were no resignations, G. Deterling volunteered to be replaced on the Board by the new candidate, Richard Wett, M.D., of Edina, Minnesota. The vote was then taken, and Dr. Wett was elected. It was decided that the minutes of the meeting should define the one, two, and three-year Board members. G. Deterling indicated that the bylaws state that a normal Board member's term is three years, but that during the first three years there are one-year and two-year terms. Per agreement of all the Board members, Shirley Neason and Dr. Vanja Holm are the only remaining one-year term members. S. Sulzbacher, J. Schultz and A. Sechrist are two-year Board members. The remainder, including Dr. Wett, are all three-year term members. S. Neason and V. Holm were re-elected to another three-year term.

The balance of the meeting was devoted to presentations by Andrea Netten Sechrist and Dr. Vanja Holm. A. Sechrist introduced a slide and audio tape presentation produced at the Alta California Regional Center. The material, which centered around the lunch hour for three Prader-Willi children, was considered excellent by the Board members, and G. Deterling asked to have a reproduction of the material so that he could make it available on a loan basis for the various local chapters within the country. Dr. Holm then presented a preliminary summary of the questionnaire submitted to Prader-Willi parents and selected professionals. Dr. Holm stated that she expects to have a final report in the next several months and would make it available to the association for distribution to the membership.

The meeting was then adjourned.

PRADER-WILLI SYNDROME ASSOCIATION
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