

# THE GATHERED VIEW

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Shirley Neason, Editor  
147 South 294th Place  
Federal Way, Washington 98003

Newsletter of PRADER-WILLI SNYDROME ASSOCIATION

Gene Deterling, President

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## PRESIDENT'S MESSAGE

Most of us who are parents have by now had the experience of eating in a restaurant with a Prader-Willi child. In many cases there's real joy in watching the child's eyes light up as the waitress approaches the table with a tray of what the child thinks is a special treat. In other cases, some of us have had a look of horror as the waitress arrives with a plate three times as full as we expected. Some of the children's plates somehow turn out to have larger servings than the adults. It is unfortunate that stealing needs to be condoned, but I think most of us who have been in that situation, when for the good of the Prader-Willi child, we have had to distract him/her long enough to steal some of the excess from the plate. And look out if you get caught, because we all have been lecturing to our children for years about the evils of stealing food!

We recently spent several days at a resort in northern Minnesota and, being on the American Plan, ate all of our meals at the resort restaurant. It was a pleasure for the most part, but we did have our moments of shock. It seems some restaurant cooks just love to see kids eat, especially when they're a little chubby anyway, and the children's portion comes out looking like a family serving. After about two days of stealthily snitching portions off his plate, our seven-year-old son, Curtis, became wise to us and remained constantly on the alert against pilferers. We had a choice though. Let him gain a pound or two or create a scene the restaurant would never forget. We opted for the former and decided that from now on restaurants have got to be treated just like schools. We're going to have to counsel the kitchen help before each meal just like we do teachers before each school year.

I've decided one way to handle this situation is to have some little cards printed to hand to the waitress from now on when she takes our order. The card will probably read something like, "Caution, my child has a very rare syndrome called Prader-Willi and has no curb on his/her appetite. He/She also requires only about half the calories of a normal child, so please make sure his/her serving is truly a child's portion or less. Please skip the (sour cream, sweet rolls, chocolate sauce, butter, gravy, etc.)"

If anyone else has a better idea or a better note to print on the card, let us know. I'm sure you know the problem. Please share your solutions with all of us.

----- Continued on Page Two



## **PRESIDENT'S MESSAGE (Continued)**

We have tried to include as much beneficial information as we have available in our newsletters. Unfortunately, all the information in all the newsletters does not answer all of the questions you have. The Handbook for Parents attempts to answer many of the questions that most people ask. We also have additional information sheets that may be of interest to some individuals. We have not listed all of them before because of the lack of copies. Now, however, we have reproduced most of the material and offer it to our membership. The following is some of the material we are able to provide.

- Synopsis sheet
- Back issues of THE GATHERED VIEW
- PRADER-WILLI SYNDROME - A Brother's View
- State listings of Prader-Willi Syndrome Association members
- Bibliography
- General Dietary information
- Speech information
- Summary data
- Media announcements (What our organization is all about.)
- Physical Therapy information

We also hope to soon have a published list of known practitioners familiar with the syndrome, and a list of facilities that have had experience with Prader-Willi people.

The Handbook for Parents should be ordered from Mrs. Neason at:  
147 South 294th Place  
Federal Way, WA 98003

It is \$2.00 a copy to members for the first copy, \$3.50 for additional copies and for non-members.

All of the material listed above, except the Handbook, is available free from our home office here at:

Box 392  
Long Lake, MN 55356

Although the material is free, it takes some of our precious funds to produce, handle and mail, so we encourage those who can afford it to send a tax-deductible donation with the request so that we can afford to be able to provide the maximum amount of service to our membership.

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One of our members who want to assure that we can continue to grow and serve you persuaded her church group to assist us in our efforts. As a result, we received \$200 from the proceeds of the rummage sale of the Benevolence Committee of The Woman's Society of the Winnetka (IL) Congregational Church. We are most grateful to Mrs. F.H. of Illinois and the Congregational Woman's Society.

## **UPDATE ON WISER ACRES**

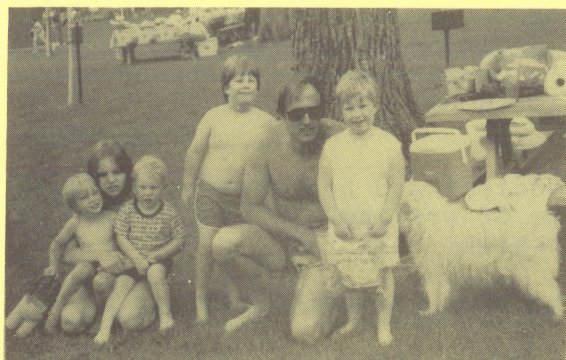
WISER Acres, a group home in Bothell, Washington, which accepts only young people with Prader-Willi syndrome or similar problems, is filled to capacity and is running as smoothly as one could expect a group home to run. There has been some recent frustration as the state inspectors changed their minds about what kind of fire alarm system was needed, and required the previous system to be

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## GATHERED REPORTS

### Minnesota



At the Minnesota Picnic, Curtis Deterling and Sara Abbott, two Prader-Willi children, pose with Curtis' dad between swims. Other family children are alongside.



Sara Abbott, her little brother, Wendy Vernig, and Curtis Deterling stayed close to the picnic tables when the word was out that lunch was coming up.

### **Minnesota Membership Picnic**

Well, it started out like doomsday, but for those who survived the trip, the Minnesota Members Picnic was well worth the effort. The picnic had been planned for almost two months, and all Minnesota members and their families were invited. Almost everyone had planned to attend. Came the day, however, and the sky began to look as though it was mad at the world! Many of our courageous members decided to chance it anyway and began heading for the picnic area on Lake Independence. Some of the people were as far as three hours away. By 9:30 in the morning, unfortunately, the whole sky fell apart and began dumping tons of water all over the area. The wind picked up, and tornado watches were issued. Five inches of rain later, about noon, the clouds became exhausted and just plain went away as fast as they had come.

With the sun now smiling on the picnic grounds four couples showed up complete with families, lunches, and swim suits. The remainder of the group had either turned back or were stranded on flooded roads.

Regardless, it turned out to be a very happy event with most of the Prader-Willi people meeting for the first time others just like themselves. There seemed to be an immediate camaraderie among them which made the whole affair worthwhile. They swam together, played together, and ate together. A couple of the older girls agreed to write to each other after having shared a few hours friendship. All in all, it turned out so successful, it's been decided to do it again soon. Reported by Gene Deterling



Kathy Olson and Wendy Vernig became good friends and swam together during the afternoon. Kathy is an excellent swimmer and has won a local area swimming award which we hope to tell you more about later.



## GATHERED REPORTS (Continued)

### Australia

Here is the kind of action we like to see! In July we received the following letter:

"With reference to my establishing a Prader-Willi organization here in Australia, after waiting weeks to hear from Rebecca's pediatrician concerning my requests for names of parents with children afflicted with Prader-Willi, I have to date received no such information.

Not to be daunted, I have approached local medical and health authorities, which has proved to be most helpful. At this time of writing, we are in the process of obtaining names of parents with Prader-Willi children.

I have already contacted two such parents who show great interest in a Prader-Willi organization being established.

The local organizations here in Campbelltown are also assisting me in contacting the national press, television, etc., in our effort in locating parents right throughout Australia.

My local minister is kindly helping me in getting a newsletter started."  
Pearl Simpson, Campbelltown, N.S.W.

Then, just before going to press, we received this letter:

"We are proud to inform you that a Prader-Willi organization has been formed here in Australia. At a Public Meeting on the 21st August 1978 a committee was formed and an organization set into motion.

We are very proud indeed that we have formed a P.W.S. Organization, because since appearing on media programmes and getting coverage in Newspapers, with regard to Prader-Willi we have discovered thirteen children so far with the syndrome here in Australia. We know there are more, too, and our Organization will be able to give so much help and assistance."

W. M. Birkin, J. P. (Mrs.), Campbelltown, N.S.W.  
Secretary-Public Relations Officer  
The Prader-Willi Syndrome Organization

### Seattle, Washington

Seattle parents had a discussion meeting on clinic day, August 6. The major topic was plans for our children's camping experience at Double R R Ranch.

The discussion turned to individual problems. One mother mentioned need for a behavior modification program to help her son get his weight down. Judi Leconte, social worker, suggested that while the children were in camp, parents take advantage of the respite to think through problems. While the child is away, he will probably be thinking also, she said. Parents could have a plan worked out when the child returns. However, she cautioned that parents should listen to the child when the plan is presented and take into consideration his ideas and responses.

Parents were advised to contact the State Bureau of Developmental Disabilities to learn what programs and funding might be available for their children.

Nancy Couhig, R.D., served a low-calorie salad for which she had developed the recipe. She gave each a copy of that and another recipe. (See THE PROFESSIONAL VIEW for Nancy's recipes.) Even nondieters thought it was delicious.

Reported by Shirley Neason  
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**GATHERED REPORTS (Continued)**Cleveland, Ohio

The second meeting of parents and friends of children with Prader-Willi syndrome in Ohio took place at Rainbow Babies and Childrens Hospital on Saturday, June 24, 1978. It was good to see that the enthusiasm of those who attended our first meeting held over for repeat participation by all but one family. All the participants had filled out the questionnaires that we had distributed at the first meeting. In addition, several speech therapists had contacted Ms. Joan Leiptz, speech therapist in the Cleveland area, who is trying to arrange for sharing information with regard to common speech characteristics of our children.

We were pleased to hear from Dr. David Orenstein, of the Pulmonary Department, about the breathing difficulties-hypoventilation in response to increasing levels of carbon dioxide that seem to be bothering some patients with this condition, as well as their families. He has been evaluating some of our families and would be interested in evaluating more families because of the great potential benefit to patients of knowing they may have deficient breathing responses. There was a great deal of enthusiasm among the group for evaluating all the information as possible for helping their children.

There was considerable interest in inviting a speaker to be concerned with decreased sensitivity to pain that appears to be so characteristic of this condition. Therefore, we would like to invite Dr. S. J. Horwitz, Pediatric Neurologist at Rainbow Babies and Childrens Hospital, to help them understand better the nervous systems of their children and the importance of any neurological differences for their long term care.

It was suggested that some help with dietary matters might be advantageous, and one of our most enthusiastic children suggested that our next meeting be a picnic with all diet foods. We are working to this end, and feel that perhaps a September Saturday might be best for such an event. We would try to incorporate Dr. Horwitz's visit, testing in Dr. Orenstein's office, and evaluation of speech characteristics into an extended day of work, fun, and communication at Rainbow Babies and Childrens Hospital. Dietary counseling will also be available.

We would like to survey those interested in such a half-day session for date preferences. Possible times include September 9 and September 23. Also we're inviting suggestions for subjects to be discussed over the coming year.

Reported by Ruth P. Owens, M.D.

Orange, California

Ida Dacus, the nutritionist at the Orange County Regional Center, another parent, and myself are in the process of trying to get a Parent Group organized. We have just a few names, but Regional Center is going to put notices in papers, etc., to find others. I personally feel groups like this are needed just to talk to others who have the same problem in their family.

Reported by Jackie Martens

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 \* THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME  
 \* ASSOCIATION, and is sent to all members. Membership dues are \$10.00 per year\*  
 \* for the U.S., Mexico, and Canada; \$13.00 per year for overseas members. Send\*  
 \* dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, Box \*  
 \* 392, Long Lake, Minnesota 55356. Editorial material may be sent to THE \*  
 \* GATHERED VIEW, 147 South 294th Place, Federal Way, Washington 98003. \*  
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**THE GATHERED EXCHANGE**Speech Development

Our little P-W girl is four years old this August and is walking well now, but is very slow verbally. She makes some consonant sounds, but still has never said Da-da or Ma-ma. Is this especially unusual?

Bowel Control

Bowel control is a real problem. My boy is 8-1/2. Do you have any advice or information on this?

Speech Development

Our son has a speech delay; in addition, he is having a slight problem with stuttering. I was wondering if other parents have experience this?  
(This mother did not say how old her child is.)

From Illinois

Hypogenitalism

Our son had surgery for undescended testes last winter. He was given hormone shots first with no results. When the urologist performed the surgery he discovered hernia on both sides. He was able to find testes and bring them down. They were small, but at this point he believes they may be functional. Praise the Lord!

From Illinois

Temper Tantrums

My daughter is seven and like a lot of children, the word NO is usually a threat to her rights. At times I feel that she starts a power struggle because it's an enormous fulfillment. It's very unpredictable from one moment to the next. In one instance she seems to be in touch with what's happening; in the next she's out of touch completely, becoming extremely stubborn and literally throwing her weight around. She's generally cooperative and fun-loving, yet without warning she'll tantrum or make absolute refusals to the extreme. Because of her development she grew up almost on a one-to-one with myself and professionals which has caused a great deal of adult dependency. Trying to break this pattern has been quite frustrating for both of us. Yet she desires the independence and acts out because of this. She's quite strong and weighs 65 pounds--trying to remove her is near impossible, for she fights with such vigor and intensity. If there's any input I can receive, please write.

From Minnesota

Recipe: Yogurt ShakeIngredients:

1/2 cup low-fat yogurt  
1/4 cup skim milk  
1 exchange of any fruit or combination of fruits  
1/2 cup cracked ice  
Few drops almond or other flavoring  
Artificial sweetener equivalent to one tablespoon sugar.

Method:

Combine all ingredients in a blender and whirl for ten seconds.

Approximately 120 calories.

1 fruit exchange

3/4 milk exchange

Makes a thick, frosty shake.

Based on a recipe in Sunset Magazine

Hypogenitalism

I would like more information about surgery for undescended testicles; the pros and cons and dangers of not having it. My son has already had one unsuccessful operation and his doctor is contemplating a second. I cannot see him having a second one when the first one failed. From Connecticut



## **THE MEDIA VIEW**

### Home Life Article:

We have been able to obtain a few copies, both new and used, of the July issue of Home Life magazine, which contained an article by the editor about her personal experience with Prader-Willi syndrome. If you have not been able to obtain a copy of this magazine from a nearby Southern Baptist Church, you can send to THE GATHERED VIEW for a copy. If you want the entire magazine, please send 60¢ to pay the cost of an envelope and postage. If you want the article torn out and sent to you, please send a self-addressed stamped envelope with your request.

### Menus

Margo Thornley, director of WISER Acres and Double R R Ranch is working on getting the menus used in her group homes and camp printed into a booklet. We will let you know when they are available.

### The Exceptional Parent:

If you have a child in public school in the United States, try to get a copy of the August issue of The Exceptional Parent. The issue has an entire section dealing with Public Law 94-142 which requires that on or after September 1, 1977, each child receiving special education services must have an individual education plan (IEP).

### On Making a Will:

Parents concerned about how to make their wills to provide to the best advantage for their handicapped children can obtain information by sending 55 cents for a booklet, "How To Provide For Their Future", to the National Association For Retarded Citizens, Box 6109, Arlington, Texas 76011.

### A Book About Books:

The U.S. Department of Health, Education, and Welfare, in cooperation with the Montgomery County (Maryland) Association for Retarded Citizens, has published a book called "A Reader's Guide for Parents or Children with Mental, Physical, or Emotional Disabilities." The book contains a list of books that are relevant to all handicaps on how to teach, train, and play at home; a list of books by parents and others who have had direct experience; a list of books about specific disabilities; a list of books for children; and a list of sources of further information. Order DHEW Publication No. (HSA) 77-5290 from HEW, Public Health Services, Health Services Administration, Bureau of Community Health Services, Rockville, MD 20857. The price is \$3.00.

## **WISER ACRES UPDATE (Continued)**

torn out and a new one installed. This has been taken care of.

An indication of how at least one resident feels about WISER Acres can be gleaned from a note he wrote to the counselors, thanking them for helping him get his weight down and asking them to continue giving him the love and understanding which he needs so badly.

We would like to remind our readers that WISER Acres and Double R R Ranch group homes and camp are owned and operated by a private nonprofit organization. They are not operated by or sponsored by Prader-Willi Syndrome Association or the Child Development and Mental Retardation Center of the University of Washington. PRADER-WILLI SYNDROME ASSOCIATION does lend support to these projects because we feel they are performing a needed function. However, the ultimate responsibility lies with the parent or guardian to evaluate whether or not the residences or camp will adequately meet the needs of their child.



**MENUS FOR A MEASURED DIET**

Since Mrs. Thornley is planning to make the Double R R Menus into a booklet, we are going to try to get menus from other sources for this column. This is a menu I developed myself. Although my measurements are not exact in some areas (I did not measure individually the different vegetables in the salad or the Japanese vegetables), I think the caloric counts are accurate enough to keep my child's weight in line. If you have menus that your child likes, please send them to THE GATHERED VIEW so they can be shared with others.

**800-Calories-Per-Day Menu**

Breakfast:	Calories:
1/4 small melon	30
1/2 cup oatmeal	74
1 cup nonfat milk	80

Lunch:	
1 ounce pressed ham	40
1 cup mixed salad vegetables	30
Zero salad dressing	0
1 cup nonfat milk	80
1/2 cup strawberries	28
1/4 cup cottage cheese	58

Dinner:	
3 ounces chicken, baked in Teriyaki sauce	170
1/2 cup rice	80
1/2 cup raw cabbage	12
1 tablespoon diet Italian dressing	10
1 cup nonfat milk	80
1 cup Japanese vegetables (Mixture of green beans, broccoli, onions, mushrooms, seasoned with soy sauce)	40
1/2 cup diet gelatin	8

For recipe for Teriyaki sauce, see the September, 1976, issue of THE GATHERED VIEW. Recipe for Zero Salad Dressing is in the July, 1978, issue.

**For 1,000 Calories, add:**

Breakfast:	Calories:
1 medium egg	72

Lunch:	
1 slice whole wheat bread	60
1 teaspoon chili sauce (spread on bread for sandwich)	6

Dinner:	
1/4 cup cabbage	6
1 Tablespoon diet Thousand Island dressing	30

**For 1,200 Calories, add all of the above, plus:**

Breakfast:	
1/2 cup nonfat milk	40

Dinner:	
1 ounce chicken	57
2 Ry-krisp crackers	42
1/2 cup apple juice	60

**For 1,400 calories, add all of the above, plus:**

Dinner:	
1/2 slice bread plus 1/2 teaspoon margarine	
1/2 cup ice milk in place of gelatin.	102

Snack:	
1/2 cup nonfat milk	40
1 gingersnap or vanilla wafer	21

**UPDATE ON DOUBLE R R RESIDENCE**

At the residential unit of Double R R Ranch, houseparents have been hired, and some of the summer campers will be staying on as permanent residents. Scott and Corinne Cameron are the houseparents; Scott is a special education teacher. One of Scott's hopes is that someone will donate money for a swimming pool at the residence.



## HEY! THAT'S GREAT!

Special recognition to the following professionals:

BETTY SCHULTZE, M.A., Assistant Professor at Saint Louis University, Saint Louis, Missouri, as part of her doctoral level program in Education has been supervising the remedial program of a child with Prader-Willi syndrome and has done her dissertation research into the Prader-Willi syndrome. Mrs. Schultze is planning further research on the educational needs of children with the syndrome.

PAULA SCHMIDT, M.O.T., O.T.R., who contributed exercises for developing strength to our Parents Handbook, has received her Master of Occupational Therapy degree from the University of Washington.

LYNN MCMAHILL, Administrator of WISER Acres, group home for young people with Prader-Willi syndrome in Bothell, Washington, has been elected secretary of the Washington State Association of Group Homes.



### A Jogger in Action:

This is Danny Neason on his daily job. Danny, an eleven-year-old with Prader-Willi syndrome, started jogging with his parents in March, and by June had worked up to the point that he was jogging three miles without stopping. It proved to be a very beneficial form of exercise, as it brought his weight down, slimmed down some of the flabby areas, and improved his posture.

### Send More:

Please send your pictures and achievements for this column. I know that some teenagers and adults with Prader-Willi syndrome read the newsletter. What have you done that's great? Lose a hundred pounds? (Or even ten?) Participate in a Special Olympics event? Get a swell new job? Do some volunteer work to help others? Write us about it, and we'll print it. If you want your picture in the newsletter, send that, too.

## ¿ SE HABLA ESPANOL?

We have received a request from a clinic for material on Prader-Willi syndrome in the Spanish language. Dr. Adolfo Pérez Comas, director of the Medical Genetics Department and Pediatric Endocrinology Section of the Mayaguez Medical Center, Mayaguez, Puerto Rico, has been kind enough to volunteer to translate a synopsis of the Parent's Handbook. He is currently attending the International Genetic Congress in Moscow, and will begin work on the translation when he returns in September.

If you know of any others who might need material in the Spanish language, please let us know. If there is enough need, we could perhaps get a Spanish-speaking person to write an occasional column for THE GATHERED VIEW.

Now that the synopsis has been prepared, I am sure it would also be possible to get it translated into other languages if there is a need. Let us know.



## THE PROFESSIONAL VIEW

Recipes by Nancy Couhig, R.D.:

### CHICKEN AND CHERRY TOMATO SALAD WITH AVOCADO DRESSING

1/2 small, very ripe avocado  
Dash noncaloric sweetener  
2 teaspoons leaf basil, crumbled  
2 dashes liquid hot pepper seasoning  
1 green onion, minced  
1/3 cup imitation mayonnaise  
3 cups cooked chicken, cubed  
1 head lettuce, shredded  
1 pint cherry tomatoes, halved.

#### Dressing:

- 1) Peel, pit, and mash avocado
- 2) Combine with mayonnaise, sweetener, basil, hot pepper, and onion.
- 3) Add water until proper consistency of pourable dressing.

#### Salad:

Toss chicken, lettuce, tomatoes, and dressing.

Yield: Four servings.

Calories in dressing: 206 per cup  
14 per tablespoon

Recipe adapted from Family Circle

Calories per recipe: 1217

Calories per serving: 306

If white meat only is used: 280

### TUNA, ORANGE, RED ONION, WATERCRESS SALAD

2 tablespoons red wine vinegar  
1/2 teaspoon salt  
1 teaspoon leaf oregano, crumbled  
1/4 teaspoon pepper  
2 cans (7-1/2 oz. each) tuna, drained and chunked  
1 cup slivered celery  
1 bunch watercress, washed and trimmed  
4 cups Romaine lettuce, broken (1 large head)  
3 navel oranges, peeled, halved lengthwise and thinly sliced  
1 small red onion, peeled, thinly sliced, and separated into rings.

#### Dressing:

Combine vinegar, salt, oregano, and pepper in a jar. Shake to blend well.

#### Salad:

Toss tuna, celery, watercress, lettuce, oranges, and onions. Pour dressing over salad.

Yield: 4 servings

Calories per recipe: 999

Calories per serving: 250

## THANK YOU!

Many thanks to all of you who have sent your stories, suggestions, and information for the newsletter. This is what makes THE GATHERED VIEW--your contribution. Please keep the letters coming. We welcome material for all columns and departments of THE GATHERED VIEW. Incidentally, one reader reported to Mr. Deterling that a letter he had sent THE GATHERED VIEW had been returned marked "Undeliverable." To avoid such a problem in the future, I suggest that you put the editor's name, Mrs. Shirley Neason, on all correspondence. The address of the newsletter is my home address, and a substitute mailman might not know this. This is especially important in the near future, as we plan to move in late September or early October. After that the address of THE GATHERED VIEW will be 26931 S.E. 403rd, Enumclaw, Washington 98022.



## A VIEW OF WHO'S WHO

Sometimes I edit the letters that come for this column in order to help readers understand them better. However, this mother for whom English is a second language tells her story so beautifully that I left most of it the way it was. I don't think you will have any problem understanding it, especially when you understand that in the Spanish language b and v are pronounced the same:

"I will like to talk about my son, M. He is twelve. Right now he is in camping in Upper Lake. We send him up there because of the booklet last year, and he want to go this year also. Like I say before, I like to talk about him, but probably I can't do it in a letter; at least I need a book. He is so wonderfull and he is our blessing. Of course, we have many problems, like I know (because I recibed THE GATHERED VIEW for two years) all the parents do have.

I like to know if is another child in this area, because Mike is the only one in school (special class in regular school) with this sindrome. Even some doctors that he saw, they do not know about the sindrome. He was diagnosis by Dr. Williams of Kaiser Hospital, even that they call him a Mistery Boy.

We have problems with his weight and is even hard for us because our food is so rich. We are from South America (Ecuador). Mike speak Spanish and English no too clear, but he tried and is improbe all the time. Even that like probably you note my broken English, but his two older brothers help him a lot.

He has the picking problem, sometimes very bad, sometimes nothing at all. He help himself with playing with shoe strings; that was his idea and (it) works. He loves puzzles--the hard ones (1000 pieces and 500 pieces)--Lite & Brite tiles, and then he don't pick.

He is a little bit strong to pain, but he complains like any other kid when he fell or bump, or stomach pain, or headache. He is afraid of shots because hurts. He is going next week to Stanford to possible surgery for the undescended testes. He already has two exploratory surgeries and I am very nervous and worried to see him suffer, but I know is for his own good.

Thank you for your time and please excuse my English."

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Most of our letters for the WHO'S WHO column are from mothers, so we were delighted to get this story written by a father:

"Our son is five years old, and has done quite well judging from some of the letters from other parents. He is three feet six inches tall, and weighs about sixty pounds.

B. was born in October, 1972, in Texas. He weighed six pounds one ounce at birth. Born three weeks early, he was force fed for three weeks and in a controlled environment for three days. He had a weak cry and hardly any movement.

Military doctors took a muscle biopsy and sent a sample to Bethesda Naval Hospital. The report came back that B. had definite Werdnicks-Hoffman disease. He was treated for this disease until April 1976, at which time a pediatrician diagnosed Prader-Willi syndrome.

B. scratches and picks sores until they are bleeding freely. Cutting the nails back helps relieve this problem somewhat. He seems to feel little or no pain. For example, he sticks his tongue on a hot toaster and puts his hand on a hot burner. He seems to take two to three seconds to realize pain.

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**A VIEW OF WHO'S WHO (Continued)**

Speech is hard to understand, but improving. Word repetition is the only help. His mentality, tested by a psychologist, ranges at three to three and a half.

He steals and hides food from the refrigerator. We now use the chain and lock method. He belches up food at will to re-eat.

He would wet the bed if my wife didn't wake him before she retires so he can relieve himself. He is very hyperactive, which we understand is rare with Prader-Willi syndrome.

B. had to be propped up in a sitting position to sleep until he had his tonsils and adenoids out. It seemed that they were so enlarged that when he lay down they were blocking his breathing passage. Under the strain of breathing his heart became enlarged and a heart murmur was discovered. The operation corrected this problem. His last physical showed nothing abnormal. He now has normal breathing.

Now some things we are proud about. B. is very much the charmer, and gets along with children of all ages. He enjoys watching baseball and football on TV and going to the Little League games. He excels in playing baseball. He can hit a baseball a country mile. He rides a tricycle quite well and plays well by himself, whereas he doesn't have to share. He knows the limits of his yard, although every once in a while he will take off by himself. He lives to be praised about things he does. B. has two older brothers that are teaching him how to box and wrestle. He enjoys this very much. We are proud of his accomplishments and look forward to many more."

**PRADER-WILLI SYNDROME ASSOCIATION**

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