
PRESIDENT'S MESSAGE

I have just started a new book that claims to provide the answers to our impending economic crisis. Not only does the author purport to provide the answers but he claims that they are based on simple truths that everyone else ignores in their flighty descriptions of the problems and the consequent complex solutions. Does that sound familiar, don't we all, at one time or another, claim to possess the answer to a problem that should be obvious to anyone that just took the trouble to "see it my way"? I prejudged the book in this manner and have only read the introductory chapter, but there are some basic truths that he has presented that are not easy to argue against. Restated, his basic rule is that human effort is directed toward perceived individual gain. Or, we will do whatever seems worth the effort.

It doesn't really take long to visualize how pervasive a concept this is. Why did I get out of bed this morning? First, because not to do so might prove economically unsound, if you are selling yourself in a service industry, failure to deliver results in loss of future requests to serve. It could also be that my particular physiology tells my body that it will be less uncomfortable if I get up and get going, as opposed to lying in bed and get a progressively increasing sensation that the mattress is turning to stone. Whatever the truth of the particular situation, something motivated the action. This is usually the case even though on occasion we do perform an action in a reflex response to a stimulus. On the way to work this morning I experienced both types of action. I grew up and lived in sometimes icy Milwaukee for forty years before I discovered the constant warmth and beauty of California. This illusion was shattered as I drove down a canyon road, to the hospital, that was marked by flares, police and a car over the edge. The motivation to drive cautiously was intense, yet when I actually hit the ice long dormant reflexes kept me from driving inappropriately and I made it safely to work.

The opposite side of the question is how do we motivate people to accomplish the action that we might believe is the proper course. We hear this question all the time when we discuss our children. How can I motivate my son or daughter to work hard enough in school so that their abilities can be used to the best advantage to them? How can I motivate myself to accomplish all the things that I know I can do but which I find less desirable to do in place of another course of action (or possibly inaction)? College courses, night schools, how-to books, religious tracts, community lectures are loaded with how to motivate techniques. I always figure that the more answers a problem has, the less likely any of them are to be useful.

Now what has all this rambling on got to do with the Prader-Willi Syndrome Association? You guessed it. The whole point of this is how can I motivate the members to recognize a need and to act on it. Like most organizations, the need is money and the action that needs motivation is sending a donation. Last summer, at a meeting in Boca Raton, Gene Deterling pointed out in his report of the treasurer, that the only thing that kept the PWSA in the black was the donations. I would like to add some year end statistics to that statement.

Membership is up twenty-five percent.
Revenues are up nineteen percent.
Cost of operation is up fifty-four percent.
Donations are down fifty-seven percent.

I have been told that the strongest and most effective motivation comes from within each of us.

Delfin J. Beltran, M.D.
President

CAMPING

A member shared the existance of Camp Leemar in Lockawaxen, PA with us. She states that the camp is quite expensive and hard to get a placement but it is a two month camp, approved as a summer school and has everything a PW child needs. She also states the camp director has had quite a lot of experience with PW children.

FRUIT SNACK

Grind 3 cups of pitted dates and 1/2 cup of raisins. Mix in 1 cup chopped nuts. Knead with hands and form into a roll. Roll in ground nuts or coconut. Wrap in waxed paper and chill thoroughly. Cut into 36 slices.

1 slice = 1 1/2 fruit exchange, 74 calories, 13 gm. carbohydrate, 1 gm. protein, 2 gm fat.

HIGH FIBER DIETS

Is a high-fiber diet for you? If you are a diabetic, the answer is a resounding "yes!" according to researcher Dr. James W. Anderson.

And if you are suffering from heart desease, obesity, high blood pressure or some colon diseases, a high-fiber diet may be just what you need.

Anderson, who is chief of medical services and director of the Metabolic Research Unit at the Lexington, KY Veterans Administration Medical Center, discusses dietary fiber in his new book, "Diabetes, A Practical New Guide to Healthy Living."

During the last 10 years, Anderson and his research team have successfully formulated a special diet and exercise program for treating and controlling diabetes. Its main component is a high-carbohydrate, high-fiber meal plan known as the HCF diet. The diet is based on 1,000 to 2,200 calories and contains 37 to 74 grams of dietary fiber. Anderson contends that his plan need not be dull and unappetizing, and that it can be adapted for the entire family's eating life style.

The book offers a flexible meal regimen with a wide selection of foods that can be substituted and interchanged. A handy guide gives the grams, calories and fiber content.

NYS PW ASSN.

Rita Welch, President of the NYS PW Association informs us that her group has been very busy and have managed to accomplish the following achievements:

1. The State of NY, Office of Mental Retardation and Developmental Disabilities NY State listing, has included PWS as a group who should get service.
2. Rhinebeck Country School, Rhinebeck, NY was the first NYS school accredited for PW children.
3. Approaching NYS Assemblymen and Senators to aid on broadening legislation for admittance on children who are 1/2 again as much as they should weigh. Asking for search and find for association.
4. Struggling to open first residence in NY State, respite care facility and emergency admittance.
5. Opening of a PWS clinic at Nassau Hospital with Dr. Jack Sherman and Roberta Ebert as Director of Pediatric Genetics and Genetic Counselor.
6. In addition to electing Rita, the group has Maxine Geller as Vice President, Dobbie Reiss as Secretary and Charles Welch as Treasurer.

Rita also wrote they were saddened by the loss of Robert Lazarian on November 3rd. Robert weighed over 400 pounds and had just had his 20th birthday. We offer our sympathies to his mother, Mary.

Rita has a stack of papers many inches thick that testifies to the efforts that she and her group have been expending in order to obtain some of the above achievements as well as previous ones.

Rita also shared an article about pancreatic polypeptides that we have taken some excerpts. I do not know where or when this article was printed but Dr. Zipf did publish a paper in the Clinical Research journal in 1980 regarding this response.

Hormones and Obesity

Being overweight is neither attractive nor healthy, especially for a youngster or adolescent. However, it is estimated that 12 percent of young children and 16 percent of teenagers suffer from obesity. These individuals are consequently at an increased risk for developing heart disease and diabetes, concerns which have prompted an interesting research study at Children's.

William Zipf, M.D., pediatric endocrinologist, is investigating the possibility that a newly discovered hormone called pancreatic polypeptide may be directly or indirectly linked to obesity and appetite control.

His initial studies have been with victims of Prader-Willi syndrome, a rare disorder characterized in part by an insatiable appetite and by body weight often greater than 200 percent of normal. Although the hormone is normally secreted within a few minutes after the start of a meal, most of the children with this syndrome did not show any hormonal response.

The article went on to say that the studies were being done at Children's in cooperation with the Endo Dept. at The Ohio State University and its Clinical Research Center where Prader-Willi patients and a normal weight group are being tested. Dr. Zipf also stated he plans on continuing working with this syndrome and although it is too early to implicate the absence of this particular hormone for childhood obesity, understanding the role it plays in appetite control could provide an important key to solving this problem.

TENTATIVE CAMP PLANS IN PA

Negotiations are underway with the Pittsburgh Institute for Rehabilitation, to provide a 4 or 6 week summer camping experience for PW children.

A separate letter was mailed to member families with children in this age group in December. Lota was attempting to find out how many people might be interested. If you did not receive this information and you are interested, please contact her as soon as possible. There are no geographical limitations, age range is from 8 to 12 years of age, parents' financial obligation is unknown at this time. Expressing interest does not mean you are committed. Please contact:

Lota Mitchell
844 Foxland Drive
Pittsburgh, PA 15243

SODIUM CONTENT OF FOODS

Some members have expressed an interest in the sodium content of food because of their child's reactions. The U.S. Department of Agriculture has a booklet titled "The Sodium Content of Your Food" that contains sodium values from nearly 800 common food items, including many processed foods. It also provides information about the sodium content of a number of over-the-counter drugs. You can get it for \$2 from:

R. Woods, Consumer Information Center
Dept. DD
Pueblo, CO 81009 Check payable to Superintendent of Documents.

Incidentally, more extensive sodium labeling is on the way. Last July, for example, General Foods announced that it had begun labeling all its foods that contain more than 35 milligrams of sodium per serving. The Food and Drug Administration is working on a proposal to encourage widespread voluntary sodium labeling. In addition, government and industry are working on developing processed foods that contain less sodium and are palatable and safe.

One of our member's has had success with using a cook book entitled "Cooking without a Grain of Salt" which is written by Elma Bagg, published by Doubleday. For the more gourmet cook, she has also used "Claibourne's Gourmet Diet" book.

MILK SUBSTITUTE

A Texas member wrote that PWSA might be interested in being a distributor for a product "Meadow Fresh" and thereby earn additional funds for the organization. Since we do not have the staff to take on a project such as this, we were forced to tell her we would not be able to consider this. This product may be of some interest to some of our members. Food labeling laws require various names in different states but in essence it is a milk substitute. It's made of 75% sweet dairy whey and 8 oz. has 90 calories. This is as rich as regular milk so can be diluted further to reduce calories. The product comes in dry form but is nothing like powdered milk. It comes in regular white as well as chocolate. It is available in 5 lb. and 25 lb. bags. With shipping the price would be approximately \$15.50 for 5 lbs. and \$66.00 for 25 lbs. 25 lbs. of plain makes about 35 gallons of milk.

If you would be interested in more information about this product, contact Glenda and she would be happy to furnish you with more information.

Glenda Abbe, Route #6, Box 852, Waco, TX 76706
home phone (817) 662-5015

PWS MEETING HELD IN PITTSBURGH

The first meeting for parents and professionals in the Tri-State area of PA, OH, and WV was held in Pittsburgh on October 17th.

Start up funding for the daylong conference was provided by the Westinghouse Fd. Featured were Dr. David Margules from Temple University, who is an expert in obesity research and Dr. Dorothy Becker, Endocrinologist from Children's Hospital, speaking on the syndrome itself.

Parents, professionals, PW persons and siblings attended. Students from two local colleges were volunteers for the children's program. We hope to have some attendance from West Virginia at our next meeting. We would appreciate any help in getting publicity there about our next meeting which is scheduled for Saturday, May 15th. This meeting will focus on the family.

Appreciation is expressed for Westinghouse and my Co-Chairman, Patti Smith. Patti is a social worker from Western Psychiatric Institute and Clinic. She devoted many hours to this meeting and is already enthusiastically planning for the next one.

Lota Mitchell, 844 Foxland Drive, Pittsburgh, PA 15243

PW PARENT SUPPORT GROUP

The first meeting for this CT group was held on November 18th. The exchange of experiences parents had with physicians, psychologists, and the school system was one of their topics. It is interesting to note that parents of older children had negative cooperation whereas the parents of younger children are experiencing more positive benefits and assistance.

Goals of this group include:

Establishment of a PW group home

Establishment of a PW clinic at University of CT Health Center

Future Subjects to be Addressed included:

Endocrinology

Nutrition

Psychology and emotional aspects experienced by both parents and child

Their next meeting will be held at Newington Children's Hospital, Wednesday, Jan. 20th at 7:30 PM. Please contact Chairperson Claire Ledoux at 741-2201 for information.

LETTER FROM A NJ PARENT

"I had to share my good feelings with someone--so here goes. I just received a letter from Mrs. Zina Levin. She has recently opened a group home for PW in NJ. She writes, 'The State of NJ has just signed a contract with her PW home to fully fund anyone registered with them who has PWS.'"

She tells me even though I don't want placement now for my son--I should contact Dee Dee Ferruggiario, Division of Mental Retardation, Capital Place One, 222 S. Warren St., Trenton, NJ 08625 and ask her where to apply for your particular area. Your child must be registered and accepted for services so if the need does arise for placement, your child will be classified and this will cut down on the waiting time."

The writer went on to say that she visited the home opened by Zina and it was beautiful. She hopes everyone will contact Ms. Ferruggiario so the state will continue to recognize our needs.

We thank you for sharing this information with the GV.

MEMBER FAMILY SUFFERS LOSS

This letter was received in November:

"On August 29th, our family experienced a tragic accident. Amy (our PW daughter) lost her father, Pat, and her brother Mike. Amy and I were in intensive care for a week after the accident--another brother of Amy's, Nathan, came through the accident just fine.

Amy did suffer a skull fracture and the doctors feared brain damage but she is fine as well. As a matter of fact she is dealing with the loss much better than I expected.

Amy, Nathan, and I would like the association to have this memorial (a check for \$500.00 was enclosed). Please feel free to use it wherever it is needed. I am also enclosing a picture of Amy--she is eleven.

Sincerely, Mary Ann Kirby

This is Amy's Picture:



It is difficult to adequately express our sympathy to this family and to thank them for making our organization the recipient of their memorial funds. I believe it helps all of us to know that benefits can be gained when memorial funds are used in perpetuating help to those still living.

CHANGES

Last June at our annual conference a new dues structure was formed and accepted by the board. It was voted that effective January 1st, 1982 the following dues would commence:

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| Basic Membership | \$15.00 U.S., | \$20.00 non-U.S. |
| Contributing Membership | \$30.00 U.S., | \$35.00 non-U.S. |
| Patron Membership | \$100.00 or more | |

The basic membership is a raise of \$5.00 per year. This raise will cover the cost of the method of mailing this newsletter to you. In the past the newsletter was sent bulk rate and took up to three weeks to be delivered in most areas. I have recently found out even longer in some areas. The newsletter will now be mailed to you first class and hopefully will improve the length of time in reaching you.

With this change, the national office has rented a mailing machine which is supposed to be available for use in time to get out this copy. If the red tape did not get entangled you will see our new meter stamp on this issue.

LOOKING AHEAD

The last GV contained an article "A Look Back", with information regarding the formation of PWSA. This issue contains a 2nd part of our history. It also contains a "Looking Ahead" article--this one.

We are growing! Isn't that great! Great strides have been made in the amount of material we have published, facilities are being opened (homes, clinics, etc.), more and more groups are forming all over the world and from all of this we can continue our "sharing and caring" so that all of us can benefit from what is being done.

Many of you are aware of the history of our organization but many are new members also.

Last June the national board approved of the formation of guidelines to be used in formulating official chapters of our national organization. A proposal for these were approved by a majority of the board members and were submitted in December to some of the groups now meeting. Their comments and suggestions were solicited. This proposal covers a vast area (from one person wanting to start a local chapter to a large group already formed). You can see what a difficult task it would be to accomplish this. I believe this task is possible though because we all want the same thing--we all want what is best for families with children (of all ages) that have this syndrome.

Hopefully this proposal will be acceptable to most groups and we can begin accepting official chapters of PWSA.

I think of "The Impossible Dream" from Man of La Mancha, "To dream the impossible dream, to fight the unbeatable foe, to bear with unbearable sorrow, to run where the brave dare not go. To reach the unreachable star. This is my quest, to follow that star, no matter how hopeless, no matter how far; to fight for the right without question or pause, to be willing to march into hell for a heavenly cause. And I know, if I'll only be true to this glorious quest, that my heart will lie peaceful and calm, when I'm laid to my rest, and the world will be better for this; that one man, scorned and covered with scars, still strove with his last ounce of courage, to reach the unreachable stars." I think of the national PWSA as the central core to help chapters to put a dedicated PW home, clinic, respite care facility, camp, educated doctors and teachers--in every state, in every province--in every country. I don't feel this is an impossible dream--I don't feel this is an unreachable star. With our continued working together--with our continued "sharing and caring"--it can happen! It will take time, unfortunately a lot of time, but we are moving forward.

DIRECT MAIL CAMPAIGN

The national office has started a direct mail campaign to solicit donations from non-members. The purchase of mailing labels from a commercial distributor is not the best source of contacts but it is all that we have at the moment. This method requires many requests to yield few contributors but eventually will build up a list of non-member supporters.

If any members have a better source of names and addresses, or even just a list of friends that they feel may respond, we would appreciate you sharing them to add to our future mailings.

Our first mailing included 550 letters. In January about 500 more will be mailed. One response to our December mailing was "What a marvelous fund raising letter--warm, informative and very touching. Bless you in all you do!" With time, we hope to build a list of people that share this sentiment and increase our potential for developing programs, research, etc.

"A LOOK BACK - PART TWO"

Part one of "A Look Back" included some information on the actual start of the PWSA and the GV in July of 1975. The Deterlings of Harvard, MA and the Neasons of Federal Way, WA were the two couples that felt an organization and newsletter would be beneficial in working with their own children with this syndrome. Gene Deterling began forming the organization and Shirley Neason became the editor of the GV. (The national PWSA recognized their efforts in awarding them a plaque at the last annual conference). Unless you are personally involved it is difficult to realize all of the detail that is necessary to form a national organization or fill six pages of pertinent information in a newsletter. But these dedicated people did establish the groundwork for this organization.

In 1976 the typical GV included such articles as: the explanation of the syndrome, request for information (of course), report on growth (first International member registered), message from the director, a question and answer column, an article by a professional, a Who's Who column and a book review.

Articles started to appear, written by people we now consider our "experts" because of their experience with the syndrome. In the November, 1975 issue, Dr. Vanja Holm, Pediatrician and Peggy Pipes, Nutritionist, wrote an article about the dietary management. This article included the paragraph:

"Successful weight control for children with PWS requires the construction of a diet designed specifically for the individual child. Parents and anyone else who offers food to the child, including the school teachers, aunts, uncles, and friends are requested to record precisely and accurately every food the child consumes. This means that the food must be weighed or carefully measured and that the amount of any food stolen must be estimated. The child is weighed and weights are recorded both at the beginning and the ending of the periods of collection of baseline data. Because of the water shifts during any period of weight reduction, the collection of valid, meaningful information requires that a minimum balance can be ascertained and a low calorie diet suitable for a reduction of two pounds per month devised by reducing calorie intake 250 calories per day from the maintenance level."

In January of 1976 Peggy also wrote an article about the first PWS child that she worked with at CDMRC (Child Development and Mental Retardation Center of the University of Washington in Seattle). She discovered this child was consuming no more food than children of the same age and yet was gaining at an excessive weight. Weight loss was accomplished although a severe reduction of calories below that anticipated was necessary. As more children were referred to the center, Peggy was convinced that not only a reduction in caloric intake below that of others their height and weight and age was important, but stringent control of the environment to make food unavailable for stealing was absolutely necessary.

The "Message from the Director" in March, 1976 included:

"We are beginning to see signs that allow us to be cautiously confident that there is progress being made toward a better understanding of PWS and the methods of coping with it. A year ago most of us were not aware of anyone who had any dedication to resolving the many problems associated with the syndrome. Today we are happy to report that we have a number of practitioners and other professional people who are deeply interested in working toward solutions to these problems."

A TX MEMBER WRITES

"Every year for two weeks in the summer, our son gets to spend two weeks at Lions Camp with no charge to us. They also take him and bring him home. It means so much to us and he loves it. I have enclosed a list of other camps in other areas. They may have different standards and requirements etc. but it's certainly worth checking in to. Our son sometimes gains a few pounds there but all the good outweighs this. He learned to swim, etc."

The list is too long to include in this issue but I will include the camp name and city. If you are interested and cannot obtain the rest of the address or phone number, contact the national office for the information.

Camp Tatiyee, Sun City, AZ
Touch of Nature, Carbondale, IL
Camp New Hope, Mc Gregor, MN
Camp Mockingbird, Memphis, TN
Louisiana Lions Camp, Leesville, LA
Lackland AFB Camp, San Antonio, TX
Camp Dogwood Sherrils Ford, NC

Wisconsin Lions Camp, Rosholt, WI
Camp Rio Vista, Hunt, TX
Camp Tatiyee, Phoenix, AZ
Colorado Lions Camp, Woodland Park, CO
Camp Woodsmoke, Indianapolis, IN
Downer's 4-H Camp, Colchester, VT
Texas Lions Camp, Kerrville, TX

ANOTHER TX PARENT WRITES

"Keep up the good work--you people have been a lifeline to me through the years! Remind people to watch for scoliosis--no one saw our daughter's until an x-ray for her hip showed it and in fact she has two curves--we are trying a brace now."

It has been recommended that all children with this syndrome be checked for scoliosis. Routine school checks do not always catch this if the child is overweight. Frequently the scoliosis is not treated but is followed.

MANY THANKS

In December several large contributions were received by our organization. One member from PA wrote:

"Enclosed please find our check in the amount of \$100.00 as our annual contribution to PWS. My husband and I expect to be able to contribute more substantially in the next few years to help our association. I have just been elected to a 4 year term as Recorder of Deeds for our county--one of my prime reasons for wanting this job was to be able to contribute more to our PWS assn.--and now I can. I am donating this first check as a memorial for Danny Neason--he was an inspiration to us all and our daughter, now 6 years, met him at the 1st conference in Mpls. We will always remember him with love in our hearts."

Two other checks for \$100.00 were received from members, one IL member and one TX member. Since we spent \$800.00 having our handbook reprinted this month, these three contributions were greatly appreciated.

One other \$100.00 check was received from the Silver Ridge Park West Chapter #3164 of the American Association of Retired Persons, Inc. This letter stated that their membership was aware of the meaningful service being performed by our organization and as a means of expressing their appreciation they had enclosed the \$100.00 contribution to aid in the continuation of this valuable service.

These donations enable us to continue to expand what we have to offer members and are greatly appreciated.

NEW ADDRESS FOR FUND CHAIRMAN

Two issues ago our new fund raising chairman wrote an appeal to the members of PSWA. Lou has moved and would like the members to have his new address so they can continue to contact him:

Lou Levesque
13105 East 5th Street
Aurora, CO 80011

JOB INFORMATION AVAILABLE

Finding a job for PW young people after completion of high school has been a problem for some people. "Making Job Opportunities for M.R. People a Reality" is available free from ARC Research and Demonstration Institute, 2501 Avenue J, Arlington, TX 76011.

Brochures like this frequently contain valuable information for young people that are not M.R. also because they refer to similar problems.

NEW TAX ACT

The Tax Act of 1981 reduces taxes in the following amounts:

1 1/4% in 1981 10% in 1982 19% in 1983 23% in 1984

Beginning in 1982, tax payers using the standard deduction will also be able to itemize charitable gifts. The deductible limit is phased in over several years until it reaches 100% in 1986. Donors may set aside cash, securities or real property to establish annuities and trusts, receive income for life and secure an immediate gift deduction.

VIDEOTAPE AVAILABLE

"There Comes A Time" is available to organizations with a \$5.00 postage and handling charge. The running time is 29 minutes. It is a sensitive, informative videotape exploring what support groups are and why there is a growing need for them.

For information contact:

The Mental Health Association of Johnson County
7208 West 80th, Room 208
Overland Park, KS 66204 (913) 381-2707

CLOSER LOOK

Closer Look Network News published by the Parents' Campaign for Handicapped Children and Youth included an article about PWS in their December issue. The three paragraph article included a description of the syndrome, quoted our Executive Director, "Parents working alone are often not able to get appropriate medical care and schooling to meet their child's needs. Local groups, however, can more easily create an awareness of the syndrome and its effects and work to get needed services". The article also mentioned that parents in a local MN chapter had opened a home for PWS people and gave the address of the national office for anyone seeking information.

Closer Look has a wide distribution and we appreciate this publicity. The staff was very nice to work with in the telephone interviews that were held.

- HANDBOOK "PRADER-WILLI SYNDROME - A HANDBOOK FOR PARENTS" by Shirley Neason. \$2.50 first copy to members; \$3.50 additional copies & non-members.
- OVERVIEW "AN OVERVIEW OF THE PRADER-WILLI SYNDROME" by Lota Mitchell, M.S.W., \$2.50 for members; \$3.00 non-members. Recommended for professionals.
- PWS BOOK "PRADER-WILLI SYNDROME" edited by Vanja Holm, M.D., Steven Sulzbacher, Ph.D., Peggy Pipes, M.P.H. A collection of papers presented at a medical conference. Recommended for parents and professionals.
- DIRECTORY "DICTIONARY FOR CLINIC SERVICES" Compiled by PWSA Clinic Services Committee, \$2.50 per copy.

CONFERENCE PAPERS

"1979 NATIONAL CONFERENCE PAPERS" Complete Set \$10.00

Conference Introductions, Gene Deterling; Prader-Willi Syndrome, Hans Zellweger, M.D.; Synopsis of Speech & Language Testing, One Child, Betty Schultze, Ed.D.; Study of 8 PWS people in a residential home, Margo Thornley; Adults with PWS, Shirley Neason; Diagnostic & Counseling Dilemmas, Bryan Hall, M.D.; Residential School Program for 2 PWS pre-teens, Eleanor Watson, R.D.; Questions during and at close of conference.

"1980 NATIONAL CONFERENCE PAPERS" Complete Set \$10.00

Conference Introductions, Gene Deterling; Care study of larger group of PWS children, Andree Walczak, M.D.; Abstract of Sucrose Behavior Study, Peggy Otto; Due Process in Education report, Betty Schultze, Ed.D.; Behavior Change Contract Ideas; Features (Less Frequent?) of PWS, Bryan Hall, M.D.; Treatment of Undescended Testes, Stacy Roback, M.D.; Questions at Close.

INFORMATION SHEETS

SYNOPSIS, PWS & ASSOCIATION

A "COMMON SENSE" APPROACH TO DIETARY MANAGEMENT OF THE PW PERSON

PWS: WHAT IS IT? WHAT CAUSES IT? WHAT ABOUT A CURE?

SPEECH PATHOLOGY, OCCUPATIONAL AND PHYSICAL THERAPIES

ORDER FORM

- ____ HANDBOOK, \$2.50 first copy to member; \$3.50 additional copies & non-members.
- ____ OVERVIEW, \$2.50 for members; \$3.00 for non-members.
- ____ PWS BOOK, \$24.50 U.S. FUNDS; \$30.50 Overseas Airmail.
- ____ DIRECTORY, \$2.50 Per copy
- ____ CONFERENCE PAPERS 1979 Set, \$10.00,
- ____ CONFERENCE PAPERS 1980 Set, \$10.00
- ____ INFORMATION SHEETS
- ____ MEMBERSHIP, Includes subscription to The Gathered View. \$15.00 U.S., \$20.00 others.

Place order by sending check to National Office.

PRADER-WILLI SYNDROME ASSOCIATION
5515 MALIBU DRIVE
EDINA, MN 55436

BOOKS

"SLIM CHANCE IN A FAT WORLD" Dr. Richard B. Stuart & Barbara Davis Behavioral control of obesity. The program results in weight loss through a combination of behavior modification techniques, nutrition management, and controlled energy expenditure.

Complete program (includes professional book, food exchange cards, exercise card etc.) \$11.95 each. Book only (paperback) \$9.95. Revised condensed edition, which eliminates the research data is also available at \$5.95 each.

"HOME TOKEN ECONOMY" Dr. Jack R. Alvord

An incentive program for children and their parents. It outlines a system that can be easily put to use by parents. The advantages of implementing a home token economy are that parents begin to react more objectively, more consistently, and less emotionally to the behaviors of their children. Available with ten charts and a guide. \$4.95 set.

These books are available from: Research Press, Box 317760, Champaign, IL 61820. Payment must accompany order. IL residents must add 5% sales tax.

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| SLIM CHANCE, complete program | Item #0607, \$11.95 |
| Book only | Item #0608, \$ 9.95 |
| Condensed | Item #0623, \$ 5.95 |
| HOME TOKEN Book & charts | Item #1069, \$ 4.95 |

THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. Membership dues are \$15.00 per year for U.S. members; \$20.00 per year for Canada and overseas members. Send dues and change of address notices to: PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.
