

### PRESIDENT'S MESSAGE

The holiday season has come and gone and I hope you were all able to enjoy its goodness. Now we look forward to the New Year and for your PWS Association that means planning the Third National Conference.

This year's meeting will be held on the campus of Florida Atlantic University in Boca Raton, Florida and the dates are June 25, 26, and 27 (Thursday through Saturday). Boca Raton is about forty miles north of Miami and twenty miles from air connections at Fort Lauderdale or West Palm Beach.

The basis for decision making in planning this year's meetings are the questionnaires received following the prior conferences. Just as Boca Raton was selected because those who voted gave it their support, the format will be changed to permit greater involvement by those attending. After an "expert" introduces a topic, discussion groups will be formed so each of us can present our expertise or inquiry for discussion as well as having the expert available to keep our ideas in perspective with the problems. This will replace the active lecturer to passive audience type presentations.

The experts will be drawn primarily from persons working with the group of PWS persons in the Boca Raton area. In a positive effort to bring as much expert experience into the discussions, I am calling upon each of you to make a special effort. That effort is directed at you, making your local experts (expert because they have learned from working with your PWS person) aware of this conference and ask them to attend. This is a unique opportunity for the persons you have faith in to learn more from others and to make their experience known to help others. This is the only national meeting where such a wide range of experience in PWS can be reviewed.

The main areas for discussion will be keyed on:

- 1) Stress Management in the Family
- 2) Group Home Planning and Implementation
- 3) Parental Responsibility and the Appropriate Education Plan
- 4) Sex Education
- 5) Dietary Management



## PRESIDENT'S MESSAGE, Continued

In addition to these topics, that lend themselves well to the group discussion format, there are two topics that would be better presented for our total enlightenment. They are the historical/scientific development of knowledge about PWS and the legal aspects of caring for PWS persons.

Dr. Mary Lou Caldwell, of the College of Education, Exceptional Student Education, of Florida Atlantic University, will be our host as well as bearing the brunt of the effort to organize the conference for us. Since the meeting is being held in the off season, lower rents for motels can be expected and we plan to have a range of prices available. Registration is planned at twenty dollars for members and it appears that the reception dinner will be at twenty dollars per plate. There will be a program with specified children's activities and a separate activity room available for the children attending.

In conjunction with the conference, the Association will be holding its annual business meeting, election of Board Members, and reports of all the committees. I hope that you will bring with you ideas on how your Association can appropriately serve your needs, reports on regional organization activities and solutions you have found to coping with the challenges of PWS. In this regard, if there are to be meetings in the future, we will need persons with regional facilities and support who can undertake the task of hosting the meeting. Bring your bid for the Fourth PWS Conference and bring a local expert. If you have any questions or suggestions, let us know—Communicate! We will serve you better.

Delfin J. Beltran, M.D.  
President

## THE MEMBERSHIP AT LARGE

The PWS Association has been growing over the past few years, awareness of the syndrome has increased, and the availability of services for our children, patients, and clients has become a reality. More and more regional groups have been formed in the past few months, from the east coast to the west coast.

At the present time, there is no formal relationship between the regional chapters and the national association. In time to come both groups will come to recognize each has much to offer each other. The national organization serves well as a referral organization, an information clearing house, a central lobbying group and a distribution center for informational literature, to mention only a few functions. Regional chapters, thru a relationship with the national organization, can disseminate information more easily to all parts of their area. Each local experience can be helpful to all of us, if made known.

My message, for the new year, to all members is: "stop, think, and write." Stop and think of how the regional chapters can and should relate to the national association, both financially and informationally. Write to our executive director or any board member with your thoughts and ideas. Only with work and planning can we become a cohesive national group for the benefit of all PW persons.

Richard J. Wett, M.D.  
Board Chairman



### PW RESIDENTIAL CAMP PROGRAM

The Department of Exceptional Student Education of Florida Atlantic University (FAU) is sponsoring a summer residential program for persons who have been diagnosed as having PWS. This will be the 4th year we have sponsored a summer program and the 2nd year we have limited it to those individuals with PWS. The program will be primarily concerned with weight loss through physical fitness and nutrition training. The age requirement is 16 years of age and up. Participants will spend 5 weeks (June 29 through July 31) living in an FAU dormitory and will utilize recreational and cafeteria facilities on campus. The program will stress correct eating habits, exercising, training the participants toward self-monitoring of eating and exercising and training toward control of their own behavior.

FAU has offered the program at no cost (other than transportation to and from FAU) for the past 3 years. Because of the increasing difficulty in obtaining funding, they are going to be able to sponsor only those participants who are financially unable to pay either the entire cost or a portion of the cost. The majority of participants will have to assume financial responsibility for all or a portion of the cost. The direct cost per participant is \$1,000. Monies may be paid to the FAU Foundation - Exceptional Student Summer Program and are thus tax deductible. Ability to pay will not be the only criterion for acceptance into the program. Applications and admission requirements may be obtained from the national organization or by contacting:

Mary Lou Caldwell, Ph.D.  
Florida Atlantic University  
Boca Raton, FL 33431  
(305) 395-5100, Ext. 2845

Applications must be received by February 28. It is hoped that parents will participate in the PWSA National Conference to be held at FAU June 25-27, just prior to the camp.

### WISCONSIN BADGER CAMP

Badger Camp is a non-profit educational and recreational organization serving mentally and physically handicapped campers ranging in age from 3 to 91. The camp serves a wide range of individuals and ability levels, and is set up in a manner that complete food control can be achieved.

Badger Camp is located ten miles south of Prairie du Chien, Wisconsin. The summer program consists of nine one-week sessions arranged by age level from June 14 through August 15. Staffing is on a one staff member to every 1-1/2 campers level. One week fee is \$190.00. Information may be obtained by contacting:

Wisconsin Badger Camp  
P. O. Box 240  
Platteville, WI 53818  
(608) 348-9689  
Office hours: Monday to Friday, 8-4



## EDUCATION COMMITTEE

The Education Committee would like to request all members of the Prader-Willi Association to do whatever they can to educate others about Prader-Willi. It seems like an enormous task, but if everyone helps, it will eventually be common knowledge.

If any members have a particular problem with education for their child, the Education Committee would like to offer its assistance in finding a solution. Or if a member has a success story about their child's education, would you please write up the information and send it to me?

Doris Jane Miller  
238 East Court Street  
Doylestown, PA 18901

## EDUCATION

We thank a new member from Kansas for sharing some newspaper articles about her daughter. One article states Teresa, a 23 year old girl with PWS, holds the record (3,756) for daily production on the shrink-wrap machine at Johnson County Industries. It also states she is respected by fellow employees and is regarded highly by her supervisors. Despite being considered mildly retarded, Teresa has been at JCI for four years. How encouraging it is to read of a successful placement.

JCI is not a regular company. It is run by the Johnson County Mental Retardation Center. The center is interested in teaching skills to lead to outside employment. Their success rate has been about 10 percent of their clients each year.

The second article about Teresa is entitled, "Retardation: How does it feel?" which appeared in the Kansas City Star. It is an excellent article stating that Teresa and two other special guests visited a fourth grade class to show what it's like to grow up "different". The other two visitors included a counselor with the Epilepsy League and another person in a wheelchair.

Surveys conducted before and after the visits showed that children had changed their minds on such questions as whether they should go out of their way to help a handicapped person. One student said, "Now we know not to laugh at a disabled person and (when) we see a person in a wheelchair not to ignore them, tease them, don't think that they can't do things you do, and always offer to push them." Another student wrote, "I learned that no matter if you have seizures or mental retardation or anything else, you are still a human being and are just different."

The day of Teresa's visit, the youngsters played simulation games to help them experience a disabled person's world. In addition to the commands that were given too quickly to be followed, they were asked to screw together nuts and bolts while wearing socks on their hands, and to read a joke book through crumpled cellophane.

All of us have encountered professionals encouraging "normalization" of our children. How refreshing to read of programs aimed at "normal" kids teaching them to accept "differences".



## PWSA CHAPTERS

As many of you may already know, groups of parents have been meeting for several years in some parts of the country. Groups in Washington, Minnesota, Australia and Canada are examples of groups that have been meeting for some time now. A California group has become very active in their attempts to establish a PW group home in the L.A. area. Another California group has been meeting in the San Diego Area. Two parents recently organized a meeting in Eastern Pennsylvania that drew people from several states. Parents in Illinois and New York have also been working on chapters. The most recent group that we have been informed about is a group from Massachusetts that would not mind having members from other New England states as well. If I've omitted some group, please let me know.

We certainly applaud the efforts of these individuals to establish chapters in their areas and are convinced that many benefits will be derived from these meetings. Not only for the parents but the children as well. We hope that they will continue to share their activities with the Gathered View in order that others may benefit from their ideas and accomplishments.

## PAI

Protection and Advocacy, Inc. (PAI) is a private, non-profit organization that protects the legal, civil and service rights of Californians who have developmental disabilities. Federal law requires that each state have a system for protecting the rights of people with developmental disabilities.

What is a developmental disability? A developmental disability is a severe, chronic mental or physical impairment that occurs between birth and young adulthood - the developmental years. Such a disability can severely and permanently affect a person's ability to care for his or her own personal needs, to live independently, to achieve economic self-sufficiency, to learn, to have physical mobility, and to use and understand language. Developmental disabilities can include mental retardation, autism, cerebral palsy, epilepsy, serious neurological conditions and of course, Prader-Willi Syndrome.

## MENTAL ILLNESS

Mental illness is not the same as mental retardation. They are separate and distinct conditions. Mental illness is often temporary and may strike at any time during the life of the individual. Mental illness can be treated and often cured.

Mental retardation, on the other hand, occurs during the period of development, or is present from birth or early childhood. It may be alleviated through medical treatment, special education, training, rehabilitation and proper care.

When the mentally retarded have difficulty adjusting to the demands of society, the problem is usually related to limited intellectual capacity, and an inability to understand what society expects of its members. When the mentally ill fail to adjust to society's demands, it is often because their mental disorders have caused them to lose touch with reality, or their emotions interfere with so-called normal responses.

However, the mentally retarded also may have emotional problems; they can become mentally ill through frustration born of repeated failures, the humiliation of being ridiculed, and the fears that come from trying to survive in a highly complex and somewhat impersonal world.



## EATER'S SIMPLE DIET PUTS CHECK ON 'OVERDRAFTS'

We have "borrowed" an idea from Michael Z. Lewin, Independent News Alliance, and modified his numbers a bit to present a novel idea on calorie counting. His humorous article does give one second thoughts that may be worth trying with PW young people.

Open your Calorie Bank Account. Of course, to open an account you need something to put in it. So you set a daily Calorie Wage.

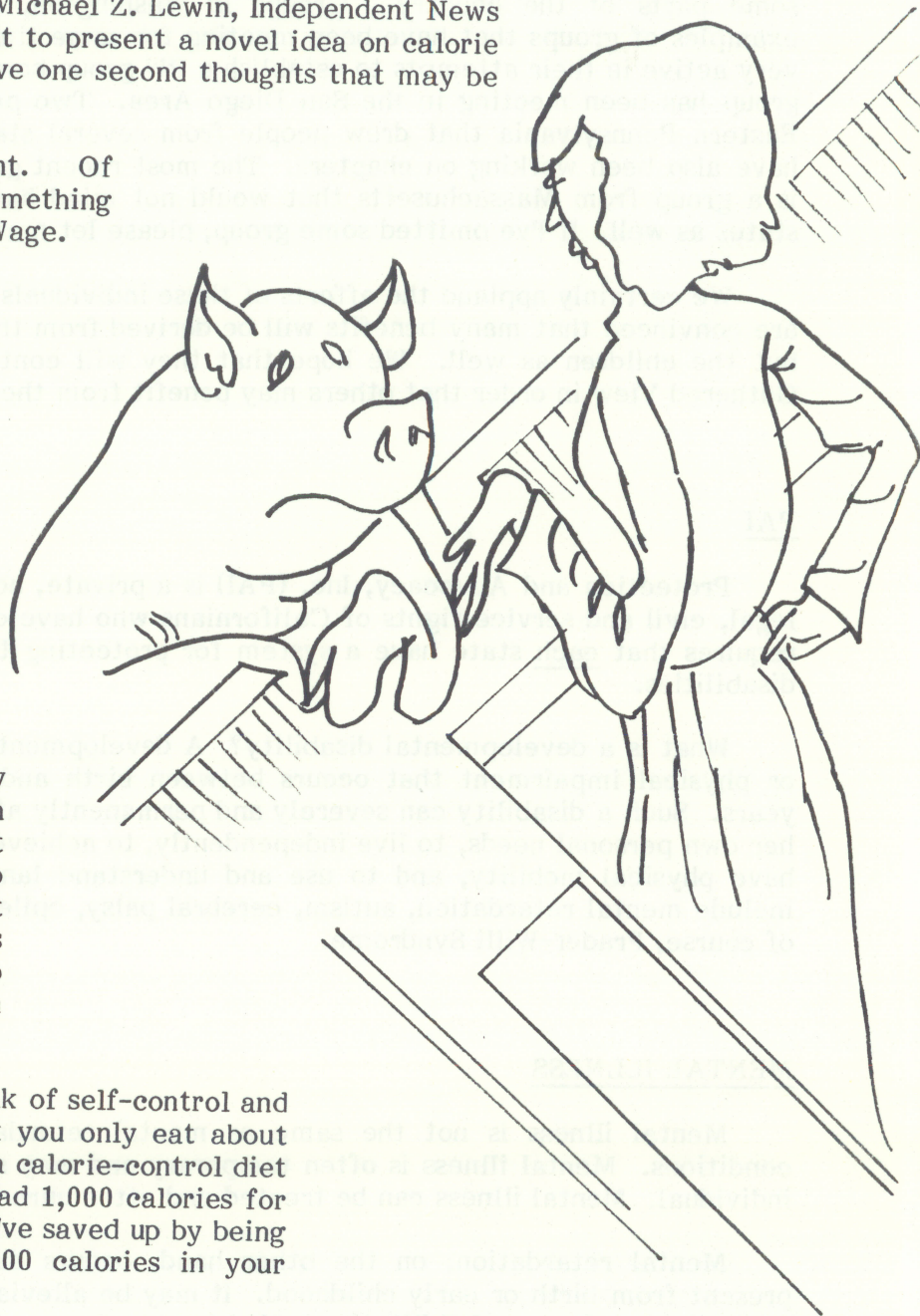
The Calorie Wage must be less than your steady weight calorie needs. Suppose you need about 1,500 calories a day to keep your weight as it is. OK, say in order to lose, we pay you a daily Wage of 1,000 calories.

They're your calories: You can spend as many as you want. The rules are you must pay from your account for all the food you eat and that you must never overdraw your account.

What I do is keep a notebook. Day 1: Balance 1,000. Spent: (write down what you ate and how many calories that totals). At the end of the day, count up all the calories you've spent and subtract it from your balance. And any of today's calories you haven't used go forward to tomorrow's opening balance along with tomorrow's Calorie Wage.

Suppose you start your diet on a peak of self-control and enthusiasm. Suppose for the first week you only eat about 800 calories a day (which is not bad for a calorie-control diet anyway). Your balance on Day 8 will read 1,000 calories for Calorie Wage, plus the 1,400 calories you've saved up by being good. On Day 8 you'll start with 2,400 calories in your account.

And if it's in your account, you can spend it. Without guilt. Go on. Have 2 Mars bars. You're still on your diet. You will still lose weight.



'SIR, YOU ARE FOURTEEN  
THOUSAND CALORIES OVERDRAWN.'  
(Cartoon idea "borrowed" from Star  
Illustrator Davis F. Matheny)



## SPECIAL THANKS

Now that 1980 has come to an end, we look back on the past year at the changes and accomplishments that have transpired in our organization.

We certainly are thankful to our members, thankful for their encouraging letters and continued support. Our newsletter continues to be great because of your continual sharing of information. The availability of materials and assistance continues to grow because of your continued financial support. Some of you may not be aware that in the past over one-half of our income has come from donations. We are very thankful for those of you that increase your dues by \$5, \$10 or \$15.00; remember us for memorial donations, and of course, those few who have made large donations.

This year brought about several major changes. The Deterlings' stepped down from their officers' positions (jobs they have carried since the founding of our group). Gene has maintained the treasurer office and both he and Fausta serve on our board in addition to their activity with the Minnesota chapter. Shirley Neason gave up the GV editor's job and now serves as our Vice-President. Dr. Sam Beltran took over as President, and the executive director position was created. Gene, Fausta and Shirley certainly deserve all our special thanks. It may not be advisable to single out a few other people for their contributions, as we certainly appreciate all of the work many others have done, too, but we feel these few do deserve recognition: Lois Olson, White Bear Lake; Karen Virnig, Minneapolis; Cellie and Ralph Ledoux, Elaine Nason and Don Salerno of Enfield; Dr. Betty Schultze, Creve Coeur; Dr. Bryan Hall, San Francisco; Lota Mitchell, Pittsburgh, and Dr. Mary Lou Caldwell, Boca Raton. The combined total of hours that these people have donated to the PWSA this past year would be unbelievable.

Thanks to a national listing put out by the Department of HHS, we recently contacted over 200 medical centers that work with genetics. At typing time, we have received 140 replies to our survey letter and 112 of them stated they had some experience treating PW people and would like their names included in our clinic services directory. This directory, being compiled by Dr. Betty Schultze and her committee, is scheduled to be published this year.

Several groups have published medical journal articles on chromosome studies and they have been presented at several medical conferences. Our dear friends from Seattle recently published a paper regarding their studies of relationships of weight and I.Q. levels. Their book, "Prader-Willi Syndrome" is scheduled for March publication. Dr. Zellweger had another paper published this year as well as Drs. Kyriakides, Sullivan and Orenstein. Maybe in the foreseeable future we will be able to say the name "Prader-Willi", without someone saying "what's that?"

Marge A. Wett  
Executive Director

## DELINQUENCY REPORT

A September, 1980 news release reported on their investigation involving the relationship between learning disabilities and juvenile delinquency since 1976. The latest findings were based on a sample of 1,617 boys, ages 12 to 15, who were classified as to the presence or absence of learning disabilities. Two groups were included in the sample: one of 633 boys who had been found delinquent by juvenile courts and a second of 984 boys who had no previous record. After analyzing the data, staff found that the presence of LD has a small, but significant negative relationship with delinquency. The results suggests that LD youths do not evidence more delinquent behavior than non-LD youths, but are more likely to be found delinquent by juvenile courts. (In other words, the LD kids seem to not be any more involved in juvenile delinquent behavior than the others - they just get caught more often!)

If you would like a copy of this report, it can be obtained through Paul K. Broder, National Center for State Courts, 300 Newport Avenue, Williamsburg, VA 23185.



## NUTRITIONAL AND EXCHANGE VALUE FOR FAST FOODS

Here is a recipe for weight watchers spaghetti. It makes two very generous servings. Serve half one day and freeze the other half for future use. This is about 265 calories per serving. Add a lettuce salad, fruit and skim milk and you have a very satisfying meal for a PW person. Another suggestion is using tomato juice on lettuce in place of dressing. It is very tasty and cuts down on the calories even in diet dressing. Another good salad is raw broccoli and cauliflower buds marinated in LoCal Italian dressing. Carrots and onions can be added.

### Weight Watchers Spaghetti

1 8 oz. can tomato sauce	)
2 stalks celery (sliced thin)	) Cover and simmer until
1 medium onion (chopped)	) vegetables are tender

1/4# ground beef	Weigh after cooking and draining all fat. Roll in paper towel to remove as much grease as possible. Combine with cooked sauce.
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1 16 oz. can bean sprouts	Cook in own juice until tender. Drain, add sauce and serve hot.
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### Chicken Salad Lord and Taylor Style

1 2/3 lb. poached boneless chicken breasts	White pepper
1 lb. celery, chopped	2/3 cup sour cream
1/2 medium onion	2/3 cup mayonnaise
1 tsp. salt	2 tbsp. fresh lemon juice

Cut chicken into bite-sized pieces. Mix in large bowl with celery. Add onion, salt and pepper to taste. Gradually add sour cream, mayonnaise and lemon juice. Chill thoroughly. 12 servings.

Per serving: 231 calories; 18 gms. of protein; 4 gms. of carbohydrate; 16 gms. of fat; 56 mgs. of cholesterol; 341 mgs. of sodium; 395 mgs. of potassium.

### Cheese Smoky

1/3 cup cottage cheese	1 tsp. chopped fresh parsley
1-1/2 oz. drained, canned smoked oysters, chopped	1/2 tsp. sherry extract
1/2 oz. scallion, chopped	1 med. tomato, quartered

Combine first 5 ingredients; pack into a container or wide-mouth insulated jar. Circle with tomato quarters; cover tightly and chill. Makes 1 serving. (Md) Per serving: 134 calories; 13 gms. protein; 4 gms fat; 8 gms. carbohydrates; 316 mgs. sodium.





On July 21, 1980, we lost our son, Scott, who was a Prader-Willi child. He was a beloved child who was a joy to all who knew him. We feel that we have been truly blessed to have had a child such as Scott to share in our home. He gave his love to all who knew him freely, without any strings attached, the kind of love that Christ, too, gives. We believe that to know Scott was to have had a glimpse of Heaven.

We, too, have had our difficult times in our search for answers to this dreadful syndrome but feel the experience of having Scott far surpasses these complex ordeals. He taught us a deeper meaning to life, to view each person as a unique individual to be recognized for their intrinsic characteristics. With each passing year, Scott grew more loving and affectionate. We believe his acceptance within the family and the community was the main contributing element to his positive self-image.

Scott underwent gastroplasty surgery and died three days later from a pulmonary embolism.

We want to say thank you to the ones who have made the Prader-Willi Association a success and the editing of *The Gathered View* a reality. You were the support we needed in our search for answers to the complexity of this syndrome. We eagerly read your newsletter and are proud to be a member of such a wonderful organization, realizing together we draw strength and courage. Also, thank you for giving us hope that some day we will have the answer to this life-consuming heartache. We can only accept our loss by realizing that life for Scott was a constant battle just to maintain a subnormal existence. Only in selfishness would we ask that circumstances be different.

Perhaps the memorial plaque placed in the Sheltered Workshop by our friends best expresses Scott's generous unique qualities. The plaque reads, "In memory of Scott Crump who was a willing worker who freely gave his smiles to the world."

Mrs. Gary Crump



## HANDBOOK CORRECTION

In the 1980 printing of the handbook, one of the items of information in the new chapter on "Life as an Adult" is incorrect. The third paragraph states that surgery for undescended testicles is usually performed before puberty. However, Dr. Vanja Holm of the University of Washington states that, in the case of a child with Prader-Willi syndrome, it is not necessary to get the surgery done before puberty. The usual reason for performing the surgery before puberty is to prevent sterility. Since people with Prader-Willi syndrome are sterile anyway, this precaution need not be taken.

## PUBLICATIONS OF INTEREST

Clinical Programs for Mentally Retarded Children, 1974, Department of Health, Education and Welfare. Available from Superintendent of Documents, U. S. Government Printing Office, Washington, DC 20402. 75 cents. DHEW Publication No. (HSA) 74-5706.

Early Intervention - A Team Approach, 1978, E. K. Allen and V. A. Holm, et al, Editors. University Park Press, Baltimore, MD. \$16.50.

Placement in Rehabilitation: A Career Development Perspective, 1979, Vandergoot and Worrall, Editors. University Park Press, Baltimore, MD.

Developing Cognitive and Creative Skills Through Art. Programs for Children with Communicative Disorders or Learning Disabilities, 1978, R. A. Silver. University Park Press, Baltimore, MD.

Report of the National Conference on Independent Living Service Regulations per P.L. 95-602, Arlington, VA, March 7-9, 1979. G. DeLong, Tufts-New England Medical Center, Medical Rehabilitation Research & Training Center No. 7, Boston, MA 02111.

## FILMS AVAILABLE

"Exceptional Times: A Historical Perspective of Special Education." Fifteen minutes, 16 mm, color, sound film. Rental fee \$20.00.

"Exceptional Times" provides the viewer with an overview of some of the significant events in the history of special education. Old photographs and film footage, interwoven with views of modern teaching and technology, provide a striking contrast between past and present.

"Individualized Education Programs for Handicapped Children." Three color, sound filmstrips, approximately 13 minutes each, designed for workshops, seminars, and conferences. Package includes "A Primer on Individualized Education Programs for Handicapped Children". 60 page manual. Package price \$65.00.

Available through: The Foundation for Exceptional Children  
1920 Association Drive, Suite 301  
Reston, VA 22091

## MEDICAL INFORMATION SOUGHT

One of our members asks if elevated white counts are consistent in PWS. If anyone has any information on this, would you please let us know?



## PRADER-WILLI SYNDROME ASSOCIATION

- HANDBOOK "PRADER-WILLI SYNDROME - A HANDBOOK FOR PARENTS" by Shirley Neason. \$2.00 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.

INFORMATION SHEETS

Synopsis, PWS and 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

Information sheets are available without charge, but a printing and postage donation is appreciated from non-members.

CONFERENCE PAPERS

"1979 National Conference Papers" Complete set \$10.00

Papers include:

Gene Deterling, Conference Introductions  
 Hans Zellweger, M.D., Prader-Willi Syndrome  
 Betty Schultze, Ed.D., Synopsis of Speech & Language Testing, One Child  
 Margo Thornley, Study of 8 PWS people in a residential home  
 Shirley Neason, Adults with PWS  
 Bryan Hall, M.D. Diagnostic & Counseling Dilemmas  
 Eleanor Watson, R.D., Residential School Program for 2 PWS pre-teens  
 Questions during and at close of conference  
 (Complete paper of Dr. Schultze available at \$6.00)

"1980 National Conference Papers" Complete set \$10.00

Papers include:

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

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ORDER FORM

- \_\_\_\_\_ HANDBOOK, \$2.00 first copy to members; \$3.50 additional copies & non-members
- \_\_\_\_\_ OVERVIEW, \$2.50 for members; \$3.00 per non-members
- \_\_\_\_\_ 1979 CONFERENCE PAPERS, \$10.00 set
- \_\_\_\_\_ 1980 CONFERENCE PAPERS, \$10.00 set
- \_\_\_\_\_ INFORMATION SHEETS
- \_\_\_\_\_ SUBSCRIPTION TO THE GATHERED VIEW, \$10.00 U.S., others \$15.00 annually

Place orders by sending  
 checks to National Office:

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



## 1981 NATIONAL CONFERENCE

DON'T FORGET TO PUT THIS ON YOUR NEW CALENDAR - JUNE 25-27, BOCA RATON, FLORIDA. MORE INFORMATION WILL FOLLOW IN THE NEXT ISSUE OF THE GATHERED VIEW.

## SHARING INFORMATION

Information on homes and treatment published in the newsletter are not recommendations, but a sharing of information. It is assumed that each individual will check thoroughly before making any decisions.

We welcome any information members would like to contribute to the newsletter. The Gathered View is the members' vehicle of communication with one another. We would like to have your response to any letters and information published in The Gathered View. We are limited in the amount of information we can publish; however, an attempt will be made to publish as much as possible. Send correspondence to the editor for publication in a future newsletter.

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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 U.S. members; \$15.00 per year for Canada, Mexico and overseas members. Send dues and change of address notices to PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436.

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PRADER-WILLI SYNDROME ASSOCIATION  
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