

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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EXECUTIVE DIRECTOR'S MESSAGE

As we turn the calendar to a new month, we begin a new season (at least in our part of the country), and fall seems to suggest a time for reminiscing.

We have a great deal to remember from the beginning of this organization, how it has grown from a handful of members with little information available, to an organization with over 1000 memberships and a great deal of materials now available. Frequently when I have the opportunity to talk with groups, I comment on the opening sentence of the acknowledgement we send to a new member, the sentence reads, "We welcome your membership in our organization". This sentence always bothers me because it should state "your" organization, not ours. I can't bring myself to change that sentence because it doesn't sound right, but I hope it doesn't take members too long to feel it is their organization.

It is very rewarding when I receive a letter or a phone call from a person in need and by writing a letter or sending materials that person's needs can be met. Over the past few years I have been saddened by the number of families that desparately need a proper placement for their young adult and nothing is available. If some of you missed the article about opening a national developmental center in the last issue of the GV, I would like to request that you go back and take a look at it. The report on the last page of this issue tells you we have gotten a start on the fund raising for this center, but we have a long way to go to have the sufficient funds to make this a reality.

Also when I talk with groups, I like to refer to PWSA as the core or center of a wheel. The core is a very important part of the wheel but with only a very few spokes, the wheel would not turn very well. You make up the spokes for our wheel, and the more of you that are active members, the more spokes and the better the wheel can turn.

Meeting the needs of 48 young adults with this syndrome right now will be a giant roll forward for our wheel. The volunteer committee is preparing a mailing right now, to be bulk mailed to you in the near future. We are asking you to become spokes by helping your fellow members in need.

Fall is a beautiful season in Minnesota, help us to color our reminiscing about PWSA beautiful too.

RESEARCH

We recently received a letter from James C. Harris, M.D. of the J.F. Kennedy Institute, regarding his study on daytime sleepiness and sleep related breathing disorders in the PWS. The three patients he has been testing reveals the most overweight patient has severe sleep apnea; one patient has moderate sleep apnea; and the third patient does not have apnea but does have some slight reduction in oxygen saturation during one stage of sleep. All three patients show excessive daytime sleepiness.

Dr. Harris writes in order to clarify the extent of the sleep disturbances, he will need to investigate additional individuals. If you live in that area and would be interested, please contact: James C. Harris, M.D., J.F. Kennedy Institute, Department of Pediatric Psychiatry, 707 N. Broadway, Baltimore, MD 21205, or phone 522-5485.

CONFERENCE, 1984

We felt you might be interested in the financial figures, and what is financially involved in presenting our annual conference. If anyone has any questions, please feel free to contact the national office for the answers.

INCOME: Registration fees and food fees: \$11,958.67

Raffle income: 6,972.78 Total Income: 18,931.25

EXPENSES: 18,731.72 BALANCE (GAIN): \$199.73

Break down:

Registration income: 8,787.67 Expenses: 11,957.84 Loss: 3,170.17 Expenses include postage, mailings, supplies, phone bills, refunds, some presenter expenses, one speaker's expenses, printing, adult banquet, coffee breaks, adult lunches, and AV equipment rental.

Raffle Income: 6,972.78 Expenses: 1,945.10 Gain: 5,027.68

Youth Activity Program Income: 3,171.00 Expenses: 4,514.66 Loss: 1,343.66 Expenses include boat rental, buses, entertainment, pavilion rental, baby sitter's lunches, banquet, lunches, pop, and AV equipment rental.

Using the above figures, without the raffle we would have had to increase the adult registration fees by \$13.00 each and the youth activity fees by \$10.00 each, in order to break even on expenses. Your continued support of the raffle has enabled us to present a top-rate conference at affordable fees. Pre-planning and executing a conference and coming in with the income and expenses within a couple of hundred of dollars is no small feat, and the conference committee should be congratulated.

WELCOME

We are very pleased to welcome the PRADER-WILLI SYNDROME TEXAS ASSOCIATION as our 11th Official Chapter.

Michael Marchitelli is president of this chapter and would be happy to hear from anyone seeking information about their group and meetings. He can be contacted at 9010 Troulon, Houston, 77036. Other officers include Ted Briggs as Vice-president, fund raising; Margaret Bell, Vice-president, programs; Jean McCall, secretary and Elizabeth Briggs, treasurer.

Mike wrote, "we at Prader-Willi Syndrome Texas Association feel that there is strength in numbers and it is through these numbers that we will make ourselves heard and recognized." We, at the national office, wholeheartedly agree and are very happy that this group is interested in working with all of the other chapters to obtain the very best for all of our young people.

EDUCATIONAL INFORMATION SOUGHT BY PARENT

A new Canadian member wrote, "Our daughter is seven years old. She is an outgoing, lively and loveable child. I write to your association in hopes that some of your members will write to me describing problems they've experienced in regards to their child's education, diet control and personalities. When Janet became of school age, she was placed into a 'Transitional Class'. This class is basically a two year evaluation period, after which the children are recommended for final school placement. Janet has been recommended for a Grade One academic class and as her parents, we have great difficulty in agreeing with this placement.

Janet has been tested by a psychologist who has confirmed our doubts. He says that there is no possible way Janet could cope adequately with the Grade One Program unless she were given at least two hours per day of resource help. This help would include speech, physical education, reading and math. With recent cutbacks in our school system, the present resource teachers are already stretched to the limit and it doesn't appear that more will be hired."

This parent is asking anyone with similiar experience to write regarding overcoming the difficulties. She also wrote, "I feel Janet should be allowed to reach her potential in life and I am determined to see that the school system will ensure this. It will be very good for my husband and I to have communication with other parents who are blessed with special children such as our Janet."

Please direct your letters to the national office and we will see that other parents can share in your experiences.

PARENT FROM UT WRITES:

We were unprepared for the changes needed to be made when our daughter was no longer involved in school. It has been difficult making the change from student to being at home. Workshop and group homes are the answer to these problems. I feel that much more emphasis needs to be placed on the transition from school to no more school. Our daughter was very bored and unhappy at home until a placement was found. A home and workshop placement has been found, we hope that both will work.

NEW BOARD MEMBER

Members attending the June conference and proxy votes, elected Suzanne B. Cassidy, M.D. to a three year term as a board member of PWSA. We welcome Dr. Cassidy as our newest member.

Dr. Cassidy received her M.D. at Vanderbilt University, then trained in both Pediatrics and Genetics at the University of Washington in Seattle. There she did a study in collaboration with Dr. Vanja Holm on the chromosome abnormality in PWS. As a consequence, she became extremely interested in all aspects of this syndrome.



When joining the staff at the University of Connecticut Health Center, Department of Pediatrics in the Division of Genetics, she organized and instituted a multi-disciplinary clinic for people with PWS, along the lines of that run at the University of Washington.

Dr. Cassidy was also instrumental in organizing a local PWS parent support group, which is now a chapter of PWSA. The clinic has grown to the following of 20 individuals, the parent's group has also grown and has recently established a group home.

In addition to her clinic work, Dr. Cassidy does Clinical Genetics and Dysmorphology and is a faculty member at the Medical School of the University. She is very interested in continuing her research work and will be presenting a paper on the chromosome deletion at the American Society of Human Genetics meeting in November in Toronto, Canada.

We are pleased to have Dr. Cassidy on our board.

BUTTONS

PWSA purchased some buttons from a member's handicap workshop and we offered them for sale at the last conference. We do have a supply left and could mail them to members It's \$1.00 for a 2½" button. The buttons have our name and emblem on them.

We also have a few left that state the conference and some that state all of the conferences have been attended. We would be happy to fill any orders.



WISCONSIN FACILITY SERVES MULTI-STATE AREA

This past month I was able to make a trip to LaCrosse, WI and visit a facility offering services to children, aged six to eighteen, with PWS as well as other developmental disabilities. I am pleased to report that I was very impressed with the services that were offered, their facility, and the genuine interest in the staff to offer a proper placement for our young people.

Chileda Habilitation Institute offers an intensive residential and habilitative program, including a blend of medical, educational, dietary, and behavioral intervention to assist each child in the development and acquisition of functional skills.

The staff provides two-to-one staff coverage and 24 hour awake supervision. Behavior Management, Physical Therapy, Occupational Therapy, Speech Pathology, Adaptive Physical Education, Art and Music Therapy, and Special Education Services are available.

The Chileda philosophy and treatment approach is directed toward offering PWS children intensive habilitation services at an age when prognosis for development and control is highest. The program goal is to have each child fill "a bucket of skills" to use in everyday life and to be successful in a homelike environment. Their philosophy also includes building on the strengths of each child with the end result being as independent as he/she can be.

Chileda is presently serving approximately 30 children and has openings. For further information, please contact: Social Services Dept., Chileda Habilitation Institute, 1020 Mississippi St., PO Box 2799, LaCrosse, WI 54602 or call, (608) 782-6480.

Marge A. Wett

CAMPING

Every year the PWS office receives requests for "successful camps" for their children. Now that your child has just finished a camping experience, would you jot down the name of the camp that he/she attended, how successful an experience it was, was weight controlled, etc., and the next time you mail in a survey or your dues include this information for us. We appreciate having some information to share when other parents ask.

PARENT SUGGESTIONS

A member wrote they had installed a dutch door (a door with separate top and bottom) in their kitchen, so the top can be opened and the mother can still supervise while working in the kitchen but the child can be kept out with the bottom closed. Sounds like a great idea for easier control.

When we eat out, we inform the waitress that our son is on a "diabetic diet". It is amazing what they will do, for example, microwaved fish instead of breaded and fried. Just ask!

NEWS RELEASES

Thomas C. Fox, editor of the National Catholic Reporter, wrote a press release and shared it with attending conference parents to take back to their own newspapers. Several parents wrote that although their paper was not very interested in the press release, they were interested in doing a more extensive article about the family. Through these efforts we obtained more awareness of the syndrome.

We thank Tom for his assistance, and the parents that took the effort to follow through on his suggestion. Tom also wrote an article which appeared in the July 20th edition of his newsweekly. The article was titled, "Painful, personal love: my Prader-Willi sister." Unfortunately room does not allow us to reprint the whole article, but we have obtained permission to share parts of it with our members.

"I am often amazed how many families include a disabled person. Although most people are not longer private about these matters, as they once were, it is true that the topic of the disabled in our families is not among the first in discussions among new friends. Maybe it should be.

In these lenlightened times, many of the stigmas once associated with the disabled have fallen by the way. We've made progress in sensitizing society to the contributions of the disabled as well as their special needs. Small examples everywhere, such as curb ramps, or bigger ones, such as special athletic competitions, attest to changing attitudes.

But much more is required. Homes for the disabled in our communities are often resisted. 'They are different,' we hear it said. I think fear often plays a role in people's reluctance to accept the disabled. Closer association with the disabled, we have learned, often help us to realize they are really not so different after all. The problem rests within us.

Yes, more work is necessary to change attitudes. We see, for example, the ominous signs in our communities that threaten the disabled—and those of us who might not claim the label. I find myself increasingly worried about the slippery slope down from 'quality of life' discussions to infanticide. Genetic and fetal research open many avenues of hope. Great scientific breakthroughs in understanding life occur each year. But, misdirected, they can lead to increased abortions as people seek 'perfect' fetuses.

Under these circumstances, those of us who have lived with and loved a disabled person have special obligations. We need to speak honestly about our joys and sorrows and those of our disabled loved ones. We need to talk frankly about our experiences, our disappointments, our embarrassments, our tears. But we also need to share some of the special life lessons that come from being close to a disabled person. For starters, I'd offer the ways such a person can unite a family or the tenderness that grows out of protecting a vulnerable person. I'd add the unexpected insights that come from opening oneself to a disabled person. Often, the wisdom and love of the disabled match the wisest and most giving among us. Finally, those of us close to the disabled need to affirm—when others might not—the intrinsic, God—given beauty we find in those we describe as disabled.

Maybe you've guessed it by now, but this is really a column sparked by thoughts about my youngest sister, Virginia, 29, one of God's rare treasures. Ginny, who suffers from a rare genetic disorder called Prader-Willi syndrome, continues to live with my mother at home. As do others with the syndrome, Ginny has a triple handicap, including slight retardation, emotional instability and obesity. The combination has made it very difficult for her to be accepted by people who do not know her."

Tom went on to a few paragraph description of the syndrome and then continued, "My sister's health continues to deteriorate, chiefly because of weight-related problems. My mother, in her 70s, finds it increasingly difficult to care for Ginny. The two are very close. They depend on each other for much personal support. My brothers and sisters and mother talk about the situation frequently, knowing Ginny's setting needs to change but not knowing quite how to change it.

It is common to find Prader-Willi children living at home—even when it might be best for them (and their families) to be given special professional care. The reasons are simple. They do not fit into any single disability classification. Local communities are not geared to care for them. Their diet requirements, their physical disabilities, their emotional and mental needs all require specialized care. But little exists. A few states have community—based group homes, but most don't. With less than a handful of Prader-Willi children or young adults in any given area, Prader-Willi relatives lack the lobbying force necessary to push public institutions to provide even modest assistance."

Tom then wrote of his attendance at the last conference, and meeting with parents desperately trying to plan their children's future; the record number of young people with the syndrome in attendance; the meeting of children for the first time; the sharing of personal stories, the laughter and considerable tears. He also compared our lack of funding and then looking at the \$300 billion planned to go for defenses this coming year.

He also commented on the unusually understanding and caring parents, " no glamour stories here, just plain people who, through circumstances they could not control, have been forced to become more generous in life than they otherwise might have been."

He continued, "It became clear at the gathering that families cannot wait for the medical professionals, communities or local governments to catch up to the needs of the disorder's victims. Parents decided to begin a fund-raiser to form a national developmental center in Minnesota to care for about two to three dozen Prader-Willi victims, to train professionals in their care and to spearhead further research into this syndrome. The goal is to put together \$250,000 to renovate and begin to staff a building being offered by the State of Minnesota. While local care remains the long-term preference of most parents, in the short term the national center provides some realistic hope.

One evening during the conference, the Prader-Willi young adults got together for a dance. Most had never before had such an opportunity. Shy at first, they soon warmed up and by evening's end were having a wonderful time dancing in a vast variety of ways. Parents standing along the walls looked on proudly, many with wet eyes. The youngsters, relaxed, away for the moment from society's scrutiny, were in their own element. To me, it appeared to be their solid vote in favor of the proposed center, which could provide an understanding environment."

Tom closed the article concluding Prader-Willi, along with other disabilities, deserves our attention and support, and added our name and address for further information about the syndrome. Again, we thank him for his support and assistance in sharing.

NEW YORK CHAPTER

The national office is continually amazed at the amount of effort that is expended by Rita Welch, president of the New York chapter. If every state had a few Ritas, we wouldn't have an identity problem.

Rita has now been invited to appear on the Community School District XII TV show, Potpourri. The show is aired on WNYE-TV Channel 25 on Thurs at 6:30 PM and Fridays at 12:30 PM. Taping will be Thurs am Sept. 13th so may follow that afternoon or the following week. Dr. Jack Sherman and Dr. Porcella will also be included in the panel for PWS. We hope all of you that can receive that program watch.

Rita has also been collecting "names" of important people to serve on the NY chapter letterhead as "Advisory Board" members. She has just received permission from Vice-Presidential candidate Geraldine Ferraro to add her name. Things are beginning to happen in the State of NY and they are all because of the tremendous efforts on this lady's part.

CONFERENCE

The 11th Annual Conference of The Association for Persons with Severe Handicaps (TASH) entitled, "New Life in the Community" will be held in Chicago, November 8-10. For more information contact: Hiroko Roe, Conference Coordinator, 7010 Roosevelt Way, Seattle, WA 98115.

SPECIAL PROGRAM

The Rehabilitation Institute of Pittsburgh held their special summer session for PWS again this year. "Wok/Walk Your Way Skinny" was the theme. Learning the use of a wok for nutritious cooking, exercise and arts and crafts were included in the program directed by a team of physicians, health care workers, therapists, psychologists and social workers, nutritionists and nurses. Increasing gross motor functioning, dietary and weight control, improving social skills, nutrition and self-control were a part of the program.

WEIGHT WATCHERS

We continue to hear reports from parents that their children have had some success with the Weight Watchers programs in various areas. One social worker reported recently that two young people received scholarships for attending regularly, and working very hard on their diets. One other mother "found" our association because of an article in the Weight Watchers publication. Our PWSA director also recently recommended contacting volunteer agencies in your area to obtain a volunteer on a regular basis to walk or do exercises with your child or take them to the local Y for additional incentive for weight control.

MIDLANTIC MEETING

The fall meeting of this chapter will be held September 22nd at the Elizabethtown Rehabilitation Hospital in Elizabethtown, PA. The meeting is held from 9:30 - 4. Dr. William Zipf (research article in this issue) will be one of the speakers. If you haven't attended one of these meetings, this month might be a good time to start.

OBESITY STUDIES

A member shared an article from the August "Children's Hospital Research Foundation" publication which contains some quotations from William Zipf, M.D. a pediatric endocrinologist and director of the Clinical Studies Center at Children's Hospital in Columbus, OH. Dr. Zipf has worked with obesity studies and the Prader-Willi syndrome for some time and has previously published articles about his studies. He stated that he has worked with 20 or so obese children with PWS and "is beginning to gain some insights into the causes of adult forms of diabetes mellitus". He indicated that children that are obese, but otherwise normal, may have a defect in a primary gastrointestinal hormone called Gastic Inhibitory Polypeptide (G.I.P.), which has shown in adults to stem from abnormal insulin secretion. Some obese children may have an abnormality in secreting G.I.P. which may make them prone to glucose or sugar problems later.

Also recently Dr. Zipf and Dr. Carolyn Romshe discovered that pediatric leukemia patients who received cranial radiation in higher dosages (now revised nationally) were subject to developing a previously unknown disorder of the brain hypothalamus. In about 15% of patients so treated, release of growth hormones was inhibited, causing shortness of stature.

It is always welcoming to read that some researchers are working in these areas.

MN COUNSELING

Since his presentation at our 1984 conference, Omar Othman of the Eating Disorders Program, has responded to requests by parents to provide individual or group counseling sessions for their children. Most of the parents expressed concern over the behavior problems displayed by their children, weight gain, and public school teasing. Under the auspices of the Associated Clinic of Psychology, Mr. Othman will now be offering these requested services. If interested in these services, please call 377-1125.

DHEA

Another member shared a clipping from The Calgary Sun, printed in August regarding DHEA, which is a compound of etiocholanolone and betaetiocholanolone, components in dehydroepiandrosterone. DHEA is used by the body to make estrogen and testosterone, female and male hormones. These experimental drugs have been animal tested and are ready for human testing. They have been found to reduce weight in animals equivalent to 20 pounds a week in humans, without any apparent side effects. Testing has also included preventing diabetes.

As with most of the newspaper articles that we read, it is encouraging to read of the prospects of medical help in the future, but we must remember it is many years before the testing is completed and the drugs approved for human use.

FIBER AND CALCIUM

"Medical Update" contained an article regarding a research study suggesting low-fat/high-fiber diets could decrease the amount of calcium absorbed by the body. The two problem areas mentioned was the fact these diets do not include many dairy products, which are the best source of calcium and also that some fibers may inhibit calcium absorption in the gastrointestinal tract. The researchers recommended taking calcium supplements if the dieters do not have a propensity to develop calcium oxalate kidney stones.

PWS & CHROMOSOMES

The question of chromosome anomalies in PWS and its significance for the possible causation of the syndrome came up several times at the June, 1984 conference. Therefore it was felt to be appropriate to update the reader of the GV about the chromosomal anomalies occurring in PWS. Chromosomal anomalies are found in about 50% of all PWS cases, though various laboratories give different incidence figures varying between 20 and 80% and even more.

Already in 1961, 5 years after the syndrome was first described, chromosomal abnormalities were reported in 2 cases of PWS. In one case (Zellweger & Mikamo, Helvetica Paediatrica Acta 16:678, 1961) a balanced D; E translocation, in the other case (Dunn et al, Pediatrics 28:578, 1961) a second Y chromosome was found. In subsequent years three further cases with chromosome anomalies were found in some cells only, while other cells had normal chromosomes. The mother of one case showed the same chromosome anomaly as her PWS child.

After 1968, methods to study chromosomes improved and it became possible to identify every single chromosome. It was then found that mostly chromosome 15 was abnormal in PWS. In many instances a small segment of the long arm of chromosome 15 was found to be absent, which is called a partial deletion of chromosome 15. In other cases more than the normal amount of chromosome 15 was present (duplication, partial trisomy, partial tetrasomy, Fuhrmann etal, Clinical Genetics 25:347, 1984). Moreover families have been observed where not only the PWS child, but also non affected family members carried the same chromosomal abnormality. Very recently Hasegawa etal (Human Genetics 65:325, 1984) studied 2 first cousins, both with PWS, the father of one of them and the mother of the other were siblings. The two PWS children, their two related parents, as well as the grandmother showed a deletion of the proximal long arm segment of chromosome 15.

In summary the following statements can be made:

- 1. There are different chromosome anomalies found in the PWS.
- 2. The same or a related chromosome anomaly can also be found in normal relatives. 3. No chromosome anomalies are found in some PWS children.
- 4. In those cases where a chromosome anomaly is found, it is frequently a partial deletion of the long arm of chromosome 15 yet the same deletion can also be found in normal relatives.

It is therefore doubtful whether or not the deletion of chromosome 15 or any other chromosome anomaly are the cause of PWS. For the time being it is wiser to speak of an association between PWS and chromosome anomalies, notably del 15q12.

Glossary: Deletion: Part of a chromosome is missing. On chromosome 15, the segment between the two arrows is often missing in PWS, it is called del 15q12.

Translocation: A piece of one chromosome is attached to another chromosome.

Balanced translocation: if the total amount of chromosome substance is normal.

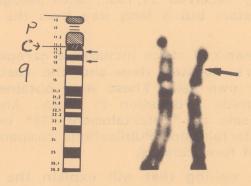
Unbalanced translocation: if the total amount of chromosome substance is abnormal by loss or addition of a segment.

Duplication: A segment of a chromosome is doubled.

Trisomy, Tetrasomy: Presence of 3 or 4 chromosomes of a kind instead of the normal pair.

Submitted by Hans Zellweger, M.D.

THE PRADER-WILLI SYNDROME



Left: Schematic Drawing of Chromosome 15
c = Centromere p= small arm q= long arm
Between the two arrows area which is missing in 50% of the individuals with PWS.

Middle: Normal chromosome 15

Right: Chromosome 15 with the deletion, indicated by arrow.

SURVEY

We would like to thank the membership for their tremendous support of the questionnaire study that is presently ongoing. At this time we have approximately 500 parents and professionals that are completing the questionnaires on PWS. When completed, this survey will contain a wealth of information that will be valuable in future research.

One parent wrote, "Please excuse the delay in my returning these forms, as I have been ill and have spent some time in the hospital. I hope what ever information I have provided will be helpful. I will forward any other information as available, and wish you well with your efforts.

These PWS sufferers are so misunderstood. The more information one can educate the public with the better, as PWS know so well and ill-informed people tend to think they are just 'over fed and over weight'. From my experience it has been a constant vigil.

As my daughter is the only PWS sufferer in our area, she doesn't make an impact on the powers that be. Publicity is all important."

Please continue to support this effort, if you are late in returning the forms, please do so anyway. If you have lost any of the sheets, we would be happy to replace them. Your efforts are greatly appreciated.

SYMPATHY

PWSA members extend their sympathies to the families of two young people with PWS that have died recently. Memorials have been received for Robert Watson and Jodi Damon. Our thoughts are with these families at this time.

NATIONAL DEVELOPMENTAL CENTER

A very important fund drive has been started. PWSA is raising money to open a national developmental center. We have already received \$9,155., with pledges of \$7,676. more. This \$16,831. is a very good start but a long way from the total amount needed.

Fund raising that is being done through the national office includes a garage sale that netted \$1000. Some of our local members donated items and the rest was collected from people's leftovers following their own sale. These were obtained by asking and giving a receipt that they had made a donation to PWSA. Another project that is getting under way is the sale of "Entertainment '85" books. Forty-eight other cities are served by the Entertainment Publications company. A phone call could get you started with this type of fund raising.

The NDC committee is presently preparing a mailing that will explain the fund raising club we have developed. We will also list the members that have already joined our fund raising efforts. We have gotten a good start with just a few members responding, we hope that all of you will feel these efforts are worth supporting.

David Leitermann, Fund Raiser

THE GATHERED VIEW is the official newsletter of the PRADER-WILLI SYNDROME ASSOCIATION and is sent to all members. The opinions expressed in THE GATHERED VIEW represent those of the authors of the articles published, and do not necessarily reflect the opinion or position of the officers and Board of Directors of the PWSA. Duplication of this newsletter for distribution is prohibited. Quotations may be used if credit is given to PWSA. 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: PWSA, 5515 Malibu Drive, Edina, MN 55436.

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