

THE GATHERED VIEW

Newsletter of PRADER-WILLI SYNDROME ASSOCIATION

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PRESIDENT'S MESSAGE

CONFERENCE TIME IS APPROACHING FAST!!

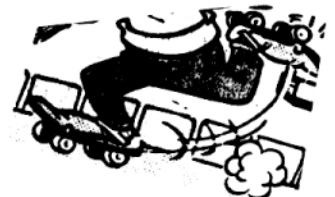
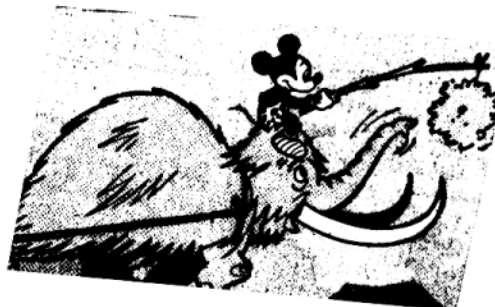
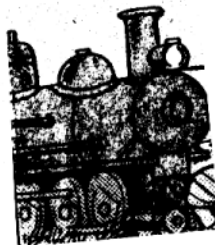
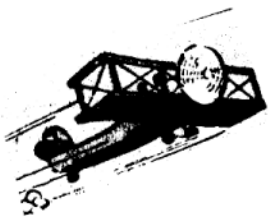
8TH ANNUAL PRADER-WILLI SYNDROME ASSOCIATION CONFERENCE

WHERE: WOODLAKE RESORT & CONVENTION HOTEL, SACRAMENTO, CA

WHEN: JUNE 19, 20, 21, 1986

WHY: The "why" needn't be answered for members who have attended a previous conference, but for those who have not been privileged to have attended in the past, it is an opportunity to spend three very informative packed days learning all of the pertinent information we are able to obtain on PWS.

HOW: The "how" isn't important, just do the best you can to get there.



CONFERENCE (CONT)

For some parents it is the first opportunity to talk with other parents, for the young people with PW this is also true, and the same opportunity for our siblings. Last year we had approximately 250 parents and professionals, nearly 100 young people with PW ranging in age from less than a year old up to 40 yrs. Most of the siblings range from the very young up to teens, with some older siblings attending the adult program.

A great deal of preparation time must be put into scheduling the adult meetings and the Youth Activity Program, which runs concurrently. Activities must be planned, costs anticipated, before submitting the pre-registration information to our membership. Hopefully we will have all of these ready, in the mail, and in your hands before the end of March. Pre-registration is very helpful to the committee, and pre-registration for the youth program is absolutely essential. Help these good volunteers out - RETURN THE PRE-REGISTRATION FORM AS SOON AS POSSIBLE.

Members have requested a form that they could duplicate and approach the professionals caring for their children to encourage attendance at the meeting. We hope you will find the form below helpful.

These are some of the young people who enjoyed last year's program:



ANNUAL NATIONAL CONFERENCE

PRADER-WILLI SYNDROME

Prader-Willi Syndrome Association

Sessions for families and professionals.
Woodlake Resort & Convention Hotel, Sacramento, CA
June 19, 20, 21, 1986

For details or pre-registration packet, please contact: PRADER-WILLI SYNDROME ASSOCIATION, 5515 Malibu Drive, Edina, MN 55436, (612) 933-0113.

BOARD ELECTIONS

Each year at the annual board meeting an election is held for members of the board. The number of members up for re-election is staggered so only three seats are available each year. Due to an increase in board size three years ago, this year's election will include five instead of the usual three.

The members of the board are very important to your organization. They are the people who represent you and make the important decisions regarding operating procedures. For this reason we have asked the board members up for re-election to share some information about them so you can be a knowledgeable voter at the conference or by your proxy vote.

We accept with regrets the decision of board member Lee Forthman to not run for a second term. Lee wrote that family and business commitments, and the fact he is planning on becoming a more active member of the Texas Chapter and 1987 Annual Conference committee, were involved with his decision not to run again. Lee was a good addition to our board, he will be missed.

Our elections are held in the typical manner of floor nominations accepted for any openings or in opposition to someone running for re-election. If anyone would like to run for the board and declare a candidacy before the meeting, we would be happy to publish information about them in the next GV.

A proxy ballot will be included with the May-June GV so everyone has an opportunity to vote for their representatives.

ENCUMBANTS:



I have a Master's Degree in Social Work and am currently employed as an Employee Assistance Program Coordinator with Westinghouse. My child with Prader-Willi is Julie, age 16. I joined PWSA in 1977 and attended my first national conference at Cape Cod in 1980, where I was elected to the Board of Directors. Since then I have:

- 1) written the "Overview"
- 2) started the Tri-State PW chapter
- 3) been instrumental in getting the Rehabilitation Institute of Pittsburgh's summer "camp" program for PWS children and adolescents
- 4) served as a national committee head on vocational training when PWSA was trying the committee approach
- 5) served on the National Developmental Center committee
- 6) spearheaded the effort to get a group home in Allegheny County ("eating disorders" home is now anticipated to open in 1986)
- 7) been re-elected to the Board of Directors
- 8) led several workshops at national conferences
- 9) survived being a PWS parent

I want very much to be re-elected to the Board for one more term before I step down for new blood. I feel that I still have more to contribute in terms of creativity, networking, organization skills, and commitment to the task that lies before all of us in helping our children and ourselves.

Lota Mitchell

ENCUMBANTS INFORMATION (Cont.)

At the 1986 Annual Conference my three year term will be completed as a member of the Board of Directors of this organization.

Working with another PW parent, we started the PW Midlantic Chapter in the fall of 1980. I served as president of this chapter until 1985. The chapter continues to meet twice a year and attempts to serve the needs of the PW families in our region.

My husband, Bobby, and I have attended all the previous PWSA conferences. We see this as our salvation, it generates ideas to take home and work on.

Margaret, our PW daughter, and I along with Barbara Johnson and her son, James, were

fortunate to appear on the Philadelphia show, "People Are Talking", with Drs. Cassidy and Brenner, presenting the facts on PWS.

Presently I serve on the Board of Directors of Doylestown Hospital, a community facility with 213 beds and also am a member of The Human Rights Committee of The Woods Schools in Langhorne, PA, a school for exceptional children. I have made several presentations to colleges, high schools and social agencies enlightening them about PWS.

PW has become a very important aspect of our lives. I would like the opportunity to continue serving the association.

Doris Jane Miller



I was a cofounder of the Prader-Willi Syndrome Association which was incorporated in 1975 when we realized that other parents also had a need for a support and information-sharing network. I participated in the everyday running of the Association until early in 1980 when operating duties were turned over to Sam Beltran and Marge Wett. I have continued my involvement as a member of the Board serving as Recording Secretary. I would like to remain on the Board because of my interest in the continuity and growth of our Prader-Willi Syndrome Association as well as the long-term welfare of our people with Prader-Willi syndrome and their families.

Fausta Deterling

ENCUMBANTS (CONT.)



As a founder of the Prader-Willi Syndrome Association I continue to have a very strong vested interest in the well being and future of the organization and, therefore, wish to continue to remain on the Board of Directors. I, likewise, believe that it is important to have continuity within the Board to insure that we maintain a clear understanding of our goals and philosophy. Having a Prader-Willi child with no long-term solution yet for his well being, I very well understand the needs of the families in our organization and wish to continue to work with the Board to promote the best possible future for all our Prader-Willi people.

Gene Deterling

TWO NEW CHAPTERS

We are happy to welcome Chapter #15, PRADER-WILLI ARIZONA ASSOCIATION and Chapter #16, ILLINOIS PRADER-WILLI GROUP. Congratulations to Tyner Kirkpatrick, President of the Arizona group and Helma Drag, President of the Illinois group. We certainly wish these groups well in further progress in their respective states.

CONFERENCE SUPPORT NEEDED

Conference registration rates have been kept down and conference papers offered to members because some of our members have helped us with a fund raising raffle. A member just called the other day and commented what a wealth of information can be obtained from the conference transcripts.

We Need Your Help Again - by member request we have lowered the price to \$1.00 again. That means we have to sell three times as many this year. We do have some left over pens with our name and address on them, some members opted to sell them instead.

Let your friends help us out by buying a book of tickets. Don't forget to order some for yourself too. Naturally unsold tickets may be returned -- and you don't have to be present to win. We'll be happy to give you a call when we draw your lucky ticket.

Help us out -- place your order today!!!

ANNUAL MONEY RAISER ORDER FORM:

Please send _____ tickets, which will be bought or sold for \$1.00, or 6 for \$5.

NAME _____ ADDRESS _____

If you would rather order some pens, they can be sold for 50¢ each. Order # here _____ If the tickets are for personal use, save time and money, just check here _____ and we'll fill in the stubs for you. Checks can accompany order or payment can be made when sold.

CONGRATULATIONS COLORADO

It was quite impressive to read the December meeting minutes for our CO chapter. Among other things, the educational slide presentation was shown seven times during the year to such groups at a county board, the Civitan Club, a children's hospital, the staff and board of a residence and the CO council for developmental disabilities.

In a survey of members, Diet and Nutrition, Parental Support and Behavior Modification were listed as the top three concerns of parents.

It's great to read of the progress that is being made by our parent groups.

ADVICE FROM MEMBER

Responding to one of our previous articles about school system problems, one of our parents from Iowa recommended that the Protection & Advocacy people are the ones to contact for help with the school system. PWSA does have a listing of these agencies if anyone needs the proper place to call. Having a "third party" to work out problems frequently is a great help.

We thank this member for sharing.

SURVEY RETURNS

We continue to receive more replies to our questionnaire survey that was completed a few months ago. No, it is not too late, anyone wishing to contribute more information can still be added to our file. This was a seven part survey, which has accumulated a great wealth of information. At the present time a program is being developed so this information can be entered into a computer system and available particularly for research. The information has already been used many times in answering questions.

A MEMBER INQUIRES

One of our members has asked us to inquire of our membership if anyone has faced the same problem they are facing. Their child with PW has developed yellow/white spots under the eyes. This condition is sometimes caused by highcholesterol but in the case testing showed this was not present. If anyone has any information, please write the National office.

RESEARCH FUND

Our Research Fund was set up as a separate fund in order to furnish "seed money" to researchers submitting proposals for larger amounts of funding or for paying for small grants directly affecting PWS. We continue to receive requests for this money and our board makes the final decision of granting these funds after requesting comments from our Scientific Advisory Board.

We appreciate members who continue to support this fund. Contributions for the months of January and February totaled \$818.25. The Total fund now has \$12,601.24. We thank members Whitlock, Van Zomeren, Becker, Maurer, Ft. Hood Federal Fund, Staples, Lennhoff, Uzendowski, Hruska, and the Frontier Chapter. We also neglected to include a thank you for the Frank Sageser memorial contribution from the PW MO Chapter which was received in November.

In December we granted a \$4040. grant towards expenses in editing a new book from this fund. We hope to have this available before the end of the year.

WE'RE GETTING TO LOVE THE MAILMAN

It's too early to shout "HOORAY" but we are pleased with the success so far of our recent funding attempts.

In January we added \$1729. to our NDC fund. (Donors included in listing below.) Many of these are repeat donors which really shows their support.

Later in January we bulk mailed a funding request to our members. As well as requesting direct donations, we asked our members to share names of friends who may also respond to our needs. As of February 23rd, we have added \$6426.28 to the NDC fund (\$5341.28 coming directly from members, \$1085 coming from friends and relatives). Forty-two members have shared names to an unbelievable total of 500 people to contact. Even though very little time has elapsed since this contact, we have already added over \$1000. to our fund. **JUST THINK HOW THIS NUMBER COULD GROW IF ALL OF OUR MEMBERS SUPPORTED THIS EFFORT.**

We extend our thanks to the following CTM Members who do care:

CTF LEVEL

Robbins, Krabsbach, Burlleigh, Eager, Boyd, Mitchell, Neason, Shadell, Wett, Notbohm

TCJ LEVEL

Ingalls, Nanzig, Flick, Fick, Wyka

UCA LEVEL

Wagstrom, Marek, the Frontier Chapter, Gunnison, Daly, Vermeulen, Deterling, Brindisi, C.Bush, Ziifle, Lehman, Hill, PW Colorado Chapter, Thompson, Valsecchi, Sidlo, Forthman, D.Miller, Reynolds, Grogger, Battersby, Sharp, Kraft, S.Miller, Ackerson, Schauer, Tobin, Ranberg, Seebach, Maurer

BCS LEVEL

Sturm, , Levikoff, Burton, Atwood, Sucha, Manning, Zador, S.Hall, Hellerman, Townsend, Redmond, Roberts, Weixeldorfer, Bodensteiner, Hermans, Lynch, Donlan, Geller, List, Howe, Maas, Brewl, Houpis, Ripley, Lincoln, Archer, Sheeran, Martsolf, Clift, Oliva, Walters, Canova, Costa, Weeks, Van Swearingen, Shepard, Schramm, S.Thomas, Youngblood, Noffsinger, Schotthoefer, Novak, Stevenson, Baer, Ballinski, O'Leary, Martin, Ray

.....SORRY ABOUT THAT

June, 1985 contributions were entered into our NDC fund but not recorded on the listing that went out to members recently. We apologize for the omission and extend our thanks to CTF members Alterman and Park; TCJ member Register, and UCA members Otteman, Tsoules and Uzendowski. We also apologize for incorrectly identifying member Rose Spear.

December, January and February contributions have started us well on the way to meeting the McDonald's challenge, but we need ALL of you to meet the NDC challenge. We're waiting for the day when the mailman rings the doorbell because the mail won't fit in the box. That's when you'll hear the "HOORAY" for sure.

DIRECT MAIL

We again tried a direct mail approach in January. This is soliciting donations from people who have no connection with our organization. A plea was mailed to over 600 people and to this date we have not received any replies. We hope this will change, but we do believe this does indicate the difficulties we face in turning to the general public for support. This is our second attempt at this type of funding, the funding experts tell us it's slow but you can build up a list of donors this way -- so far we have struck out.

Matching the McDonald's challenge will put us over \$100,000. LETS SEE THAT NUMBER IN THE NEXT GV.

ADULT PEN PALS

Upon receiving requests from a few parents, and reading about a letter magazine in the PWSA-United Kingdom newsletter, we would like to know if we have some parents who are interested in developing a "Circle of Friends" traveling letter. We are proposing that the names of five people interested in writing to other parents form a "circle". Parent or couple number one would write a letter which could include anything of interest to other parents of young people with PWS. This could be helpful tips, bragging, questions, or whatever you would like it to be. This would be mailed to the #2 name on the list. Number 2 would add their addition and mail it to #3. After the letter has gone through all five people, it would be sent to the National office. We would be able to pick up on any goodies to be shared in the GV, seek answers for any questions left unanswered and then mail the letter back to #1. Then the next circle could be started. We would form a circle for each group of five, dividing the parents by age groups.

One parent wrote she would like to have a pen pal. "I thought maybe just sharing experiences of a typical day or whatever might be enjoyable between parents, especially those of us who have no one to talk with about our common ground."

If interested, send your name and address and we'll get you started in a "Circle of Friends".

HELPFUL TIPS ON WEIGHT CONTROL

"Here are some tips which have worked for us--many are basic psychology 'tricks' or just plain common sense", a parent couple wrote.

1) Food: Out of sight, out of mind. Food preparation is delayed until the last minute before meals or done when PW is out of home. Errands are often run or games played during the hour or so before meals as a good distraction.

2) Attempt to educate the PW child as to when it's "okay" to be hungry. It's not okay immediately after a meal, but it is okay in mid-afternoon or before a meal.

3) Food deprivation can be used as a punishment. Our daughter has a small dessert at every lunch and dinner. It is the highlight of her day. However, if she sneaks anything (even a piece of cereal) or will not stop a temper tantrum, she loses her next dessert. It's amazing how well this usually works. It is difficult to predict how long we will be able to use this effectively as she grows older, but it works well now.

4) Teaching nutrition. Our daughter knows which foods on commercials are bad (as most of them are!). She'll say "that makes my tummy big" or "that has too much sugar". Our response can reinforce the thought.

5) Sometimes we give my daughter a snack before she asks for it especially if she is having a rough day or has seen others eating. Examples: rice cake (35 cal.), sugarless gum, breath mint (1½ cal), diet soda pop. This makes her feel more like the others, not left out.

6) Diet. At mealtimes she generally gets the same things that other family members get, only much smaller helpings. Using a smaller plate may be helpful. The exception: vegetables--she gets larger helpings of these. (You can always add another vegetable as a treat from last night's leftovers.)

SOUTHEAST REGIONAL GROUP FORMING

Due to the efforts of one of our parent members, Dottie Cooper, the Sparks Center for Developmental and Learning Disorders at the University of Alabama at Birmingham, are organizing a workshop for the States of Alabama, Georgia, Mississippi, Tennessee, and Northern Florida areas. This workshop will be held in July or August.

If you are interested, and have not received information from Sparks directly, please advise the National office and we will make sure you are on the mailing list for information. Future plans include developing a support group with regular meetings.

FALLING INTO THE TRAP

Unfortunately many professionals who work with people with PW, make presentations, and write about the syndrome, fall into the trap of making statements regarding symptoms and problems and leave the impression this is true in 100% of the cases.

As we hear the well known statement of "Yes, Virginia there is a Santa Claus", I feel we need to write occasionally, "Yes, there is a person with PW that does not have problems."

Letters are received and the parents state the doctor has informed them their child has a "mild case of PW". This reminds me of receiving the diagnosis of a "mild case of pregnancy." I believe we have to accept the diagnosis of PW in the same way of being informed of a pregnancy, and I feel this is a good comparison because every pregnancy is different--different from one person to another and even can be different in the same person from one pregnancy to another.

Our children do not all develop the same symptoms, all of the symptoms associated with the condition, and certainly not all to the same degree. What we do want to present to you via this newsletter and our other publications, is facts we feel you should be aware of. When we write about weight problems, when we write about behavior problems, we know that every child is not affected, and certainly some are affected to a greater degree than others. By presenting these problems to you, we hope that those people with younger children particularly will be able to prevent some of these situations by working on changes from an earlier age. We also have faith that changes will be made through research efforts. Our Research Fund is now being utilized for these purposes. Our dream of a research center affiliated with the NDC is another hope for the younger children. Remind us (the GV) if we fall into the trap too, and assist us not to be "negative" by sharing the joys and accomplishments as well as the problems.

OUR SYMPATHY

PWSA extends their sympathy to Lee Shadell's family for the loss of Betty, wife and mother. Even though we knew Betty for a very short time in her life span, it was not difficult to see her dedication to helping her family and others. As co-chair for our 1983 conference, even though her health was a problem then, Betty gave selflessly of her time and efforts. She was very dedicated to a group assisting the handicapped, instrumental in opening the San Diego PW home, and a very active member of the PW CA Foundation. She will most certainly be missed.

A PARENT WRITES

My daughter Tina is eight. Her receptive language is on target, but her expressive language is considered severe (between 2-3 yrs.). It has always puzzled me how much Tina really knew. I began to search for answers and discovered that Tina responds very well to visual cues. I purchased flash cards that have the picture and word on the same side. For words that were difficult to illustrate, I taught Tina to use deaf signs. By using signs, I taught her the alphabet, days of the week, action verbs, other words she had difficulty saying. When using signs, it is very important to remember to say the word along with the sign.

To avoid confusion, I only teach a few signs at any time. When Tina masters saying the word, we stop using the sign and choose another word and sign. Flash cards of the word and signs are made by tracing the sign and writing the word underneath. Tina studies her flash cards by herself and has begun to read. This method of using signs and flash cards has given Tina an alternative to communicate and has relieved her of the frustration of not being understood.

I hope this information will be helpful to others with similar speech problems. (We are sure it will, it has been reported before that our children respond better to more than one form at one time, for example, a picture, the written word and reading the word at the same time.)

CA SEEKING NAMES

One of our members in California is seeking the names of people who are interested in having a home in the Los Angeles area for Prader-Willi people. If you are interested, please call Toni Campoy, (818) 766-3123.

SCOLIOSIS SCREENING DANGER

The current method of screening for scoliosis has begun to worry the FDA because of the high amount of radiation exposure. Further investigation is being done on dentistry x-rays and regular chest x-rays also.

Half of the states do have screening programs to detect scoliosis in children 9-14 yrs. Although the school programs are confined to a physical examination, the FDA cautions that the emphasis placed on diagnosing has led to an increase in the number of children that have follow up x-rays. The FDA also found that many children with mild curvatures not requiring treatment were monitored periodically with x-rays to see if the curvatures were increasing and almost 50% of x-ray units tested used the best techniques for minimizing radiation exposure.

It is also a concern to PWSA that only half of the states do have this screening program. We recommend that those in states without this program make sure that a yearly exam does include a scoliosis check.

PW CA FOUNDATION MEETING

Dick and Marge Wett have been invited as guest speakers for the March 16th meeting of the PW CA Foundation. The meeting will be held at the Dubnoff Center in North Hollywood.

Further information can be obtained from Co-Presidents, Janice Shimmins and Renee Tarica if you missed the meeting notice.

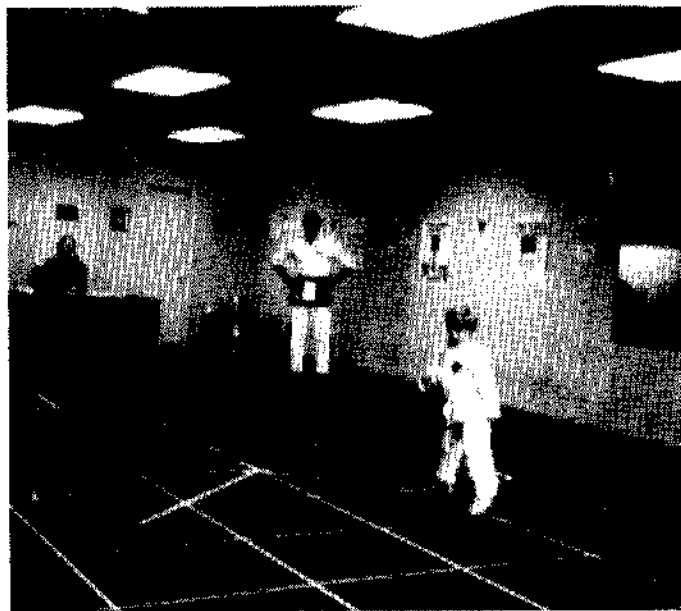
EXERCISE WITH KARATE

A mother writes, "I wanted to share with the PWSA membership how pleased I am with the Karate class my son, Michael, has been taking. After much searching, I find it to be better for him than any therapy he's had. The tenets of "Tae Kwon Do" are: Self-Control, Courtesy, Integrity, Perseverance and Indomitable Spirit. Besides increased muscle strength, better coordination, improved balance and conversion of fat to muscle; Michael is learning confidence, being a part of a special and close-knit group of kids who help each other, discipline, respect and responsibility.

He began in private lessons and after 5 months earned his yellow stripes. He is now in regular classes and is working toward his yellow belt. He's learning to jump and is very ambitious about progressing.

The key is having a good instructor. Mr. Ress knows Michael's strengths and his limitations. He has taught him to do push-ups and sit-ups, and allows him to do them in a way in which he is capable. Karate is something which can be begun as young as 5 yrs. and can progress into adulthood. Its benefits are never outgrown. Michael's confidence is growing along with his progress. He felt good enough about himself to enter the spelling bee at school. Even though he's a second grader, he came 2nd place from his entire school. We were all proud."

We're happy to be able to share this letter and also a picture of Michael.

NECESSARY INFORMATION

More and more the National office is contacted for information. Whenever one of you contacts your local representatives in the legislature, your local health departments, etc., we frequently are asked to supply statistics. How many people do need placement in the State of Illinois? How many people are there in the State of Ohio over the age of 13 with PWS? How many adults are there that do not have any services?

In order to answer these questions accurately, we must have this on file. We know we keep asking you to fill out forms, but it is because we do not hear from all of you and we know our records are not complete. It will only take a few minutes to complete the form below, why not do it right now? Numbers are very important, we can't prove we have needs without them. PLEASE HELP THOSE IN NEED NOW.

Fill out the form on the next page and return today.

INFORMATION NEEDED:

Name of person with PWS _____

Birthdate _____ Present weight _____ Race _____

What facilities have been used:

Infant stimulation _____ Type of school placement _____

Day program (type) _____

Out of home placement (type & where) _____

Facilities needed but not available _____

Return to PWSA, 5515 Malibu Dr., Edina, MN 55436

THANKS.

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., \$20.00 per year for Canada and overseas. Send dues and change of address to: PWSA, 5515 Malibu Dr., Edina, MN 55436.

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