



The Gathered View

Newsletter of the
Prader-Willi Syndrome Association

Volume XVII Edition 3

May - June 1991

CONGRATULATIONS

The Board of Directors of PWSA is happy to announce the appointment of our new President, Janalee Tomaseski-Heinemann. She will serve a three-year term.

Many of you know Janalee from sessions she and husband Al have led at numerous conferences.

Many more know her for her insightful, humorous and often poignant writings about the world of PWS which we all inhabit. Janalee chose to marry into that world when Al's son Matt, just turned 18, was only 7.

She has served on the PWSA Board of Directors for the past five years. She holds a Master's in Social Work from Washington University in St. Louis, Missouri. Since 1984, she has been at St. Louis Children's Hospital, the only social worker with the Hematology/Oncology Department serving over 200 children with cancer. She works with each family whose child is diagnosed. She has initiated and coordinates support and bereavement groups for parents, groups for the children, teen sibling bereavement groups, and a support group for nurses. She is involved in special trips, programs and camps for the children and their families. In February she was selected as the 1991 recipient of the John Krey III Memorial Award for outstanding humanitarian efforts in cancer control in the Missouri Metropolitan St. Louis area. Her personal file contains a number of treasured letters from supervisors, physicians, state officials, a graduate student she supervised, and professors at whose classes she presented. These letters contain the highest praise for her warmth and caring, high principles, teaching and scholarship, mature judgement, genuine concern for others, and unique ability to relate comfortably with all types of people. Janalee Tomaseski-Heinemann brings to the office of President of PWSA, the highest office in our organization, an outstanding professional background and a history of deep personal dedication to PWS and those affected by it. Congratulations, Janalee! And congratulations, PWSA!

by Lota E. Mitchell, M.S.W., Chairperson PWSA Board of Directors



IN THIS ISSUE

CANDIDATE PROFILES

PROXY BALLOT

FUNDRAISER REACHES \$32,000

Prader-Willi Syndrome Association
 6490 Excelsior Blvd. E102
 St. Louis Park, MN 55426
 (612) 926-1947
 Office Hours: 8:30am to 4:30pm, CST
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Barbara Whitman, PhD, St. Louis Univ.

PRE-REGISTRATION PACKETS CONFERENCE

Due to the printing and mailing costs, PWSA does not mail the pre-registration packets to all of our Canadian and other countries members. If you are planning on attending the conference or have the possibility you might be able to attend, please request this packet and we will get a copy right off to you. U.S. packets were bulk mailed and should be in everyone's mail box by now. If you did not receive a packet, please let us know.

MOLECULAR GENETIC TESTING FOR PWS

The Scientific Advisory Committee and the Board of the Directors of PWSA recommended and PWSA funded for one year a clinical service laboratory whose purpose is to provide molecular genetic testing for cases of PWS which do not have a chromosome deletion and for cases in which there is a chromosome deletion but the clinical manifestations are non-typical.

This testing will be done at the University of Arizona, Department of Pediatrics, under the direction of Dr. Suzanne Cassidy and Dr. Robert Erickson. Requirements for testing in most cases include availability of samples of both parents and the affected child, and of information concerning the clinical manifestations present in the affected individual. This testing will be provided free of charge, and funding is available for transportation costs of samples. Results will be made available to the child's family and physicians.

For more information, please contact Dr. Suzanne Cassidy, Section of Genetics Dysmorphology, Department of Pediatrics, University of Arizona Health Sciences Center, Tucson, Arizona 85724, phone (602) 795-5675, Fax number (602) 626-4884.

by Suzanne Cassidy, M.D.

AUDIO TAPE FOR TEACHERS

Member Polly White writes, ``Over the years, I have grown very tired of trying to describe PWS to teachers, principals, and other school personnel''.

Polly used the PWSA handout, 'Do's and Don'ts for Teachers', approached Patty Wheeler and Bill Lawson of WZZK FM 105 Radio in Birmingham, who unselfishly gave of their time, talent and equipment and produced an audio cassette.

Polly graciously shared a copy with us. If anyone would like a copy, please submit \$3.00 to cover cost of tape and mailing.

LOOKING GREAT!

Brent has learned to swim. It took a very dedicated lady one on one but we did it. He also got to bowl in the Special Olympics and loves it. And better yet, Brent is 15, about 5' and weighs 100 lbs. His mother writes, Thanks to all we've learned, mostly because of PWSA, it is getting easier.



THANKS PWSA

A member writes, ``Enclosed please find our donation. We are very happy to contribute to PW, without it, I do not know where we would be.''

The member continues to inform us that her daughter was successfully placed in the Oconomowoc Developmental Training Center, at our suggestion, and has gone down from 300 to 140 pounds. We are pleased with her quality of care, and the staff in charge. The member also added how her family had great fear because of her daughter's weight that if they did not find a placement for her one morning they may have had to deal with her death.

We are always happy to share success stories

COLORADO RESPONSE

The mother of a six year old shared the names and addresses of several facilities that have been of help to her in the State of Colorado, in response to our request in the last GV. She mentioned they were able to receive a monthly check for disabilities expenses (including respite care) occurring above the normal family cost. Unfortunately this mother was one of only two that did respond to our request for your input in the development of brochures for finding assistance and services in your area.

ALMOST CAMERA READY

DIRECTIONS, a new publication for parents of children from infancy to age five, is almost ready for the printers. A combination of efforts from Suellen Inwood, Dr. Cassidy, PWSA's publication committee (Lota, Janalee & Louise), and the office staff, have made this publication possible.

Chapter One, ``Questions, Questions'', states ``You probably have so many it may feel like a whirlpool inside your head. Let's begin by answering some very important questions that most parents and families ask.''. Other chapters of the book include a brief overview, how to select the right physician, information from infancy through preschoolers, medical concerns, avoiding obesity, therapies, behavior management, entering the school system, legal concerns, and you and the rest of the world. Ordering information will be included in the next issue and the books will be available at the Chicago conference.

Would you believe PWSA put out their first publication in 1978, and we now have a long list of publications and brochures.

BOARD MEMBERS

Members of the Board of Directors serve a three year term and are elected at the general membership meeting during our yearly conferences.

All four members, whose terms are expiring in July, have agreed to run for another term. PWSA procedures include listing these names on our ballot, a nomination committee presenting a slate at the meeting, and the floor open to any nominations prior to the balloting taking place during the meeting.

Proxy votes can be cast only by using the form included in this issue.

(Duplications not acceptable.)

Included on the ballot this year will also be a motion regarding partial reimbursement of traveling costs for the Board of Directors (see last GV for further detail).

Board members running for re-election include:

Stewart Maurer

Stewart and wife, Bronnie, joined PWSA in October of 1975. Their son, Andy, is known to all conference goers as he has missed only one conference since they started. Stewart was elected to the board in 1982, has never missed a meeting, and has served on several board committees, and is presently chairing the important Crisis Intervention & Training Committee.

Louise Greenswag, RN, PhD

Louise has participated in PWSA since 1982, serving her first term starting in 1985. As one of the professional members of our Board, Louise has a long list of contributions to our organization, including co-editing the management book, which has been a great addition to the materials available through PWSA. She is current co-chairing the parent portion of the first international meeting in the

Netherlands and completing a study on psychotropic medications.

Louise stated, "I seek re-election so I can continue to grow with your organization."

Penelope Park

Penny and her husband Jerry joined PWSA in 1985 and are the parents of a seven year old son with PWS. Penny is serving her first term being elected to the Board in 1988. Penny's major contribution to PWSA has been her efforts on the Fund Raising Committee, instigating the "Be An Angel" campaign which has had two successful years.

Barbara Whitman, PhD

Barbara joined our midst in 1984 and was elected to her first term on the Board in 1988. In addition to being very active with the Missouri chapter, the PW clinic at Cardinal Glennon Hospital, researching and publishing, Barbara is presently working on the very important development of new educational materials for PWSA.

She is also co-chairing the study on psychotropic medications mentioned above.

GOOD NEWS DEPARTMENT

PWSA has been approached by a prestigious publisher that formulates clinical newsletters and asked to sponsor a series of newsletters on PWS. These newsletters reach 150,000 practicing physicians and are widely read because of their quality and the fact they are short rather than included in larger journals. The publisher is now seeking financial support from a sponsoring drug company. Let's hope this is achieved in the very near future.

TERRIFIC LETTER ANDY!

From the Georgia Association for PWS newsletter:

Dear Governor Zell Miller,

My name is Andrew Louis

Alterman. I'm nineteen years old. I'm very special Handicap person with Prader-Willi syndrome. I had written a letter to Joe Frank Harris to see if he could help us. He couldn't help us to build a Group Home. Since you are the new Governor could you help us. I go to school in Philadelphia Pennsylvania because there is no program for me in the State of Georgia. Its costing my Dad alot of money to send me to school out of state. I really Love the State of Georgia very much in the whole wide world. I want to come back home. I miss my family and relatives and my Home State. I want to come back in the State of Georgia to Live. I really appreciate it if you could help we really need it. I really need a Group Home with Prader-Willi syndrome. I Thank you very much for understanding my situation and my problems. -Sincerely Your Friend Andrew Louis Alterman

LOBBYING BY CHAPTERS?

In 1976 the Tax Reform Act gave outright permission for public voluntary 501(c)(3) organizations to lobby without penalty, within specific expenditure limits.

Why are we writing about a law 15 years after it took effect?

Because the IRS recently issued regulations to interpret the law. It now states: Organizations with annual budgets of \$500,000 or less can spend 20% on lobbying. Within those limits, 25% of the total lobbying expenditure can be used for what Congress calls "grass roots lobbying", or encouraging others to take action.

GUARDIANSHIP GRANTED

A mother writes, with your assistance, we were able to obtain guardianship and conservatorship for our daughter. Your statement was very convincing to the court.

No one was certain we were being truthful and since no one involved with her case had ever heard of PWS, we needed assistance. There are now ten more people who are aware of the syndrome.

The brochures were also a help. Receiving the newsletter is also helpful, thank you again for all your help.

FAMILIES

Divorced and the chief supporter for two children (one with PW), she can't afford to lose her job but the 104 degree temp and strep throat is going to eliminate the usual day care placement. It's a nightmare come true and this doesn't have to happen only to divorced men or women. As single parents can attest, going it alone is difficult but similar events can apply to a family where both parents need to work. It can also happen to families when the child with PW is in a school system where the hours do not match the required working hours. Some children become "latch key" children as young as 8, while children with PW can never accept that responsibility. The following solutions point out you can not "go it alone". You need to work on building strengths. If you do not have a spouse to talk to, find another parent or a friend. "Talking it out" with someone else may even point out a solution to you without their input. Look for the positives in your situation, other parents may be worried about their teens driving and

dating, that may not be a concern for you.

Permit yourself to not be the only one who can care for your child.

The longer your child is completely dependent on you, the harder it will be to "let go" and share that care. Some articles in past issues of The Gathered View have found humor in difficult situations. A few people responded negatively to printing these. Humor can build strength. People who can laugh at themselves or at their situation usually feel stronger when problems do. I could continue to live with this as a tragedy in life or search for the positive contributions it made upon the world. Parents managing day to day can build on their own strengths.

PROGRAM MANAGER SOUGHT

The Glenkirk organization is the operator of an 8-bed designated PWS facility in Northbrook, IL.

Glenkirk is seeking a Program Manager to develop and implement resident treatment plans, review resident goals, supervise direct care staff, and coordinate treatment goals.

Qualifications should include BA/BS Behavioral Sciences or related field, 1-2 yrs. experience with DD, PWS knowledge preferred, with some supervisory experience and knowledge of behavior modification principles.

If interested, contact Ruth Erbach,
(708)272-5111, Ext. 215.

WE'RE SPILLING THE BEANS

Myth:

Oat bran is the best source of fiber.

Fact:

Beans are just as good a bargain, continuing rich portions of both dietary

fiber for intestinal bulk and water-soluble fiber, which helps the body lower cholesterol levels. One cup of cooked beans provides about half the daily fiber intake suggested by the National Cancer Institute. A serving of canned kidney beans contains a whopping 5.8 grams of total fiber, while a serving of dry oat bran has 4.0 grams of total fiber.

MYTH:

Beans bloat bellies.

FACT:

The more often you consume, the less you'll balloon. Build up tolerance for beans by eating small amounts, then slowly up the intake so your body can adjust to the new way of eating.

MYTH:

Beans are boring.

FACT:

Beans are not just sidekicks for hot dogs. They act as sponges, soaking up flavors of any seasonings they're cooked with. You can be creative with beans' endless, palate-pleasing ways of preparation, from simple soups and salads to entrees-even breads and desserts.

(Desserts?? What are those??)

MYTH:

Beans are fattening.

FACT:

Beans are one of nature's near-perfect foods. They are full of muscle-building protein, abundant in vitamins and minerals, low in calories, sodium and fat, and rich in tasty, hearty flavor. Toss some excitement in your life -add a variety of cooked beans to your favorite recipes.

OUR SUPPORTERS -OUR THANKS**(WE COULDN'T DO IT WITHOUT YOU)**

From mid-February thru mid-April, we were able to add the following amounts to our various funds:

Research & Operating(from Memorials) = \$ 660.00

CIT = \$ 65.00 Research = \$1220.00 Operating = \$ 271.00

Angel Fund = \$ 8362.20 Contributing & Patron Dues: \$ 1790.00

Conference = \$ 1500.00

A special thanks goes to Penny Park for arranging the matching \$7500.00 for our Angel Fund and to Lota Mitchell for arranging the Westinghouse grant of \$1500 for the YAAP Conference Program.

MEMORIALS: Hotchkiss (Williams), Pankonin, Maurer (Milliman), PWS-Utah (Payne), Uzendowski & Sojka (Abramek), Hughes (Fitzmaurice), Beckman (Jackson), and the following people for Ziifle (Owobopte, Leon, Ziifle(3), Jung, King, Reid, Deterling, Thalheim(2), Olson, & Wett), Evetts (Clark), Daly (O'Hara).

CIT: Parent, Olson(2), McAndrew(Seyb). **RESEARCH:** Quadrel Foundation, Weiner, VanZomeren(2), Notbohm, Boyd(2), Willinsky, VFW(Krebsbach), Winnebago UF(Doolittle), Jones (Abramek), & Castle.

OPERATING: Notbohm, Winnebago UF(Doolittle), Castle, UF-Ohio.

ANGEL FUND:

CHERUBS: Fondell, Kelleher, Taylor, Evano, Anonymous, Bartolucci, Goodman, Valsecchi, Marchitelli & Powel. **ANGELS:** Abramek & Wachter.

ARCH ANGELS: Dooley, Hughes & Lyons. **HEAVENLY ANGELS:** Dolese Bros.(Park)

DUES CONTRIBUTORS: Burke, Eggers, Endres, Belliard, Casey, Shepard, Vandergriff, Gootzit, Tippie, Hammill, Sheeran, Daly, Pflieger, Sturm, Stenger, Gorman, Weger, Luhman, & Brady.

DUES PATRONS: Whitehead, Notbohm, Cheng, Lehman, Baron, Furr, Metzger, Herrmann, Burleigh & Singer.

Total contributions for this year's annual fund raiser (Be An Angel) now totals \$32,063.20.

Since dues, material sales profits, interest etc. is not sufficient to meet operating costs, progress can only be made by relying on donations.

WE ARE MOVING FORWARD WITH YOUR SUPPORT

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WE MADE THE SOCIETY NEWS

A recent Detroit Free Press article on the upcoming marriage of Lee Iacocca and Darrien Earle (which has now taken place), included a mention of Darrien's charity work for Prader-Willi syndrome. Darrien is the vice president of the board of Quest, a corporation formed to raise money in conjunction with the PW California Foundation. This group has not only raised a great deal of money, but has introduced the syndrome to many VIPs in the state.

MEMBERS QUESTION MEDICATIONS

It is generally published that medications to control the food intake of people with PWS do not work. For most part, we believe this to be true but we do continue to read articles where some success is reported. A recent article (Dech, Budlow, 1991) reported some success with the use of Fluoxetine. A 22 lb. weight loss occurred over a 6-mo. period of treatment, and also reports less compulsions (in this case, less hair pulling). Another short term fenfluramine administration (with 15 people), produced significant weight loss, improvement in food related behavior, and a decrease in aggressive behavior directed toward others (Seikowitz et al, 1990).

These authors suggest some medications may serve as short-term interventions.

Parents frequently report that their child was hospitalized for weight loss (because of severe health complications) and have produced very little weight reduction. Generally the problem is that the calories are not reduced significantly to produce rapid weight loss. The hospitalization time is short and by the time they reduce the intake sufficiently, they are ready for discharge. A consultation with some of our PW experts is certainly recommended if this becomes a possibility for your child.

Sympathy

Is extended to the family of Ita Mae Ziffle. Robert and Ita Mae joined our organization in the Spring of 1976. Their daughter Kari has PW. Ita Mae was a lovely lady who will be missed.

PREPARING A LETTER OF INTENT

"Letters of Intent" are mentioned when you take the first steps to preparing your estate plans. In many ways, it is the most important document that you will prepare because it will help all involved interpret your desires for your disabled child.

Although it is not a "legal" document, like your will and trusts, the courts do rely on it for guidance in understanding your wishes. It may be addressed to "To Whom it may Concern" or addressed directly, it can be typed or handwritten. You may include any information that you feel would be of help for future care providers to give the best possible care and support. Once you write the letter, sign and date it. It should be reviewed each year, situations do change. Some of the following information may be included: Family History; Child's Overview, Education, Employment, Living Arrangements, Social Environment, Religion, Medical History. Be certain you include a description of behavior management (those tried and results), final arrangements desired for your child, and any other information that you feel will help future care providers in giving the best possible care and supervision.

FLORIDA CONFERENCE

Florida is making efforts to develop a state chapter. Contact Sandra Stone, 6135 Turtle Mound Rd., New Smyrna Beach, 32169, to put your name on their mailing list for information.

A conference will be held in mid June in Gainesville.

GOOD LUCK FLORIDA!

MORE BENEFITS

Thousands more disabled children are expected to become eligible for federal benefits under regulations issued in February by a Supreme Court ruling. Not only the children's medical problems, but also the effect those conditions have on walking, eating, dressing and other daily activities, will qualify them for Supplemental Security Income (SSI). SSI benefits average \$387 per month but amounts granted vary due to circumstances involved.

NEW YORK CAMPING

The PW New York Association has arranged camping again this year, special PW week being July 1st through July 6th. Up to 76 campers can be accepted. Camp Wilton is located in northern Saratoga County, foothills of the Adirondacks, near Saratoga Springs. Campers must be between the ages of 17 and 40.

If not filled with New Yorkers, it may be possible for neighboring states residents to apply.

Wilton's number is (518)584-3110.

DISABILITY?

Early one morning two were talking, one had a child with a disability the other not. The one woman said must you grieve so over the fact your child is disabled. The other responded well I had a lot of choices to make. I had to choose:

My attitude,

I could continue to live with this as a tragedy in life or search for the positive contributions it made upon the world.

My expectations,

One path being totally realistic and warding off any false hopes of things never accomplished. This path can also lead to false despair, for it will lead you to settle for less than the best of all possible worlds for your child and family.

The second path whose foundations are hope and optimism and whose journey entails struggle against the limits that the 'realists' set. After all realists do not live with your family, they know the norms.

To pursue excellence or settle for mediocre services. It sometimes takes a fight to get what I know to be right for my child. Face the world on my own or build a network of strength.

Committing oneself to excellence opens one to building partnerships with professionals, other parents, and most of all the family. I have seen families that have become focused on the disabled child rather than be focused on the family and the potential network around them. Finally, shall I control all the days of this child's life or do I set my sights on their life without my total control.

I have to remember all parents let go of their children at some point in time to live life with the support of other people. The other woman replied, you are right, you have a lot of choices in your life, when will you know if you made the right choices?

She replied probably never, but at least I will know I made a choice.

Paraphrased from Families and Disability Newsletter, The University of Kansas, Beach Ctr. on Families and Disability.

Pw Diet?

It's a new diet!! You eat anything you want and then...

You burn off all the calories arguing with everyone about what you ate!!

GRANTS--

We are pleased to announce because of your generosity PWSA was able to award two conference grants to enable two families from the States of Maine and Texas to attend the 13th Annual PWSA Conference.

--CIT Funds were also approved to help out three additional families from the States of North Carolina, Iowa and New York to attend.

--In the past families have reported what a tremendous difference attendance has meant to them. We are sorry we weren't able to assist all eleven applicants that contacted us for help.

WHO: PWSA

WHAT: 13th ANNUAL
NATIONAL CONFERENCE

WHERE: HYATT LINCOLNWOOD,
CHICAGO

WHEN: JULY 25TH -27TH

Special Note for Transportation

Cost of transportation from the airport to the Hotel will be about \$20.00 one way. Contact PWSA if you have any questions.

NEW EDUCATIONAL TOOLS--

The new slide presentation for professionals has been completed and will also be available in video form in the near future.

--A display exhibit has also been designed and is now on order.

Look for more information on these items in upcoming issues.

--Thanks to Barbara Whitman and her "connections", we will have first class products at budget prices.

CHAPTER NEWS

*** It's been a long time but we're happy to report the Kentucky residence for PW has now opened. Congratulations to all who worked so hard on this accomplishment.

*** Lee Forthman has stepped in and the Texas Chapter is now meeting again.

*** Many states are working on badly needed group home development. What do you do when you get the response from your state, "we have no money"?????

*** The last GV offered assistance in getting the Ohio Chapter started again -only one family responded.

*** PW Alliance of NY, the newest chapter has put forth their efforts and offered a two day line up for their first conference, April 26th-27th.

*** The PWS Seminar sponsored by the PWSA of PA held April 9th was reported as a great success, with over 120 professionals and parents in attendance.

*** The MN Chapter continues to press for needed residential facilities. Hopefully the three page article which just appeared in the St. Paul Press will get someone's attention.

*** The Kansas Chapter is meeting with a provider to open a group residence in Wichita. Great progress is being reported.

*** Under the direction of Paul Alterman, the GA Chapter is working diligently on mass mailings to school districts and pressing legislators for needed homes.

PROXY VOTES

++What is a proxy ballot?--

A proxy ballot gives you the opportunity to vote even though you cannot be present at the conference.

++How do I pick my proxy?--

Anyone who is going to be at the conference can act as a proxy for you. This can be a board member, an officer, or any member of PWSA. For your convenience, the board and officers are listed on page two.

++Why should you submit a proxy?--

This is your opportunity to be an active member. If no proxies are submitted, just the members in attendance will make the decisions.

++Can I tell my proxy how to vote?--

Yes, you may direct him/her how you want your ballot cast, or you may let them choose.

++What do I do with my proxy ballot?--

Give it directly to the person you choose, or mail it to PWSA and they will give it to your proxy at the meeting.

A motion notice was included in the last GV. Vote on this motion will be held during the balloting.

The motion submitted by Gene Deterling read as follows:

Whereas the members of the Board of Directors and Officers of PWSA must incur inordinate expenses because of travel to the two Board meeting locations each year and whereas the currently unreimbursable expenses make it prohibitive or undesirable for some members of PWSA to consider becoming candidates for the Board of Officers it is therefore moved that the Board of Directors and Officers be reimbursed for reasonable Board meeting expenses up to a maximum of \$500 for each member per calendar year.

PROXY BALLOT--

I would like the following person to act as my proxy in all voting transpiring during the 1991 general meeting (including vote for board members, reimbursement motion, and any other matters that may come before the board during the general membership meeting):

Name of Proxy: _____

Please vote on my behalf or follow these guidelines:

Date: _____

Signature(s) _____

Vote on Board Resolution:

_____ YES _____ NO

Must be returned to PWSA before July 1st, 1991.

THIS IS YOUR OFFICIAL PROXY and is the only legal acceptable medium to be used

(reproductions in other newsletter or phone calls are not legal).

NOW IS THE TIME TO ADD YOUR TWO CENTS

Comments are received regarding PWSA's operations and the newsletter (both positive and negative). We'd like to hear from more of you.

WHAT IS PWSA NOT DOING THAT WE SHOULD?

WHAT SHOULD BE INCLUDED IN THE NEWSLETTER?:

--Which type of articles interest you the most?

--Which type of articles should be eliminated?

Please return along with your proxy and you'll help direct your organization

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 PWSA. Duplication of this newsletter for publication is prohibited. Quotations may be used upon credit given to PWSA. Membership dues are \$20 per individual, \$25 per family, and \$30 Agency/Professionals. Any dues, change of address to: PWSA 6490 Excelsior Blvd. E102, St. Louis Park, MN, 55426. Questions and Comments regarding the publication or PWS, call (612) 926-1947.

**Prader-Willi Syndrome Association
6490 Excelsior Blvd. E102
St. Louis Park MN 55426-4797**

First Class Mail