

The *Gathered View*

National Newsletter of the Prader-Willi Syndrome Association (USA)

Coming Out of the Closet with Prader-Willi Behavior Problems

This is the title I gave to an article I wrote 26 years ago. I wonder if we have put some parents back in the closet by always talking about the success stories and how we have a "new generation of PWS." Although that is true for many families, for others their reality is this story written so honestly and poignantly by a parent today.

~ Janalee Heinemann

Director of Research & Medical Affairs

Like every parent of a child with PWS, I desperately hoped that my child would be minimally affected by the syndrome. I spent countless hours on literature, therapies, medical appointments, experimental treatments, fighting for growth hormone, talking with parents and other experts, advocating, and attending conferences. We made regular 6-hour drives to see a renowned PWS endocrinology expert. I believed that if I worked hard enough and found all the "right" things to do, my son would become one of the success stories I read about.

My vision included walking by age 2, average range IQ, minimal food seeking/behavior problems, regular classroom at school, reading and writing by first grade. A lofty dream? Perhaps. But I was driven to beat the odds. It was that image that kept me going through many difficult times. I wanted this so much for him, for our family. I was determined that I could make it happen.

It became clear early on, however, that things were not going according to my master plan. A big spike in unexplained weight gain took us by surprise at 15 months. Since he wasn't yet crawling, it was harder for him to burn calories. By age 2 the food seeking had hit hard, and still he wasn't crawling. When he finally took his first steps at age 2.5, we celebrated this milestone and promptly locked the refrigerator. By then, he was seeking food from the refrigerator, trash, sofa, floor, unlocked cars, other people's plates.

Many more setbacks were in store over the next few years, including severe behavioral challenges. Then at age



Nolan, 6, loves motorcycles, firefighters, and pretending to be a doctor.

6, another blow: school testing revealed an IQ score of 72, and private neuropsychological testing showed a 59.

I grieved and mourned the loss of my vision for my son. I wondered: How had this happened? What had I done wrong? What stone did I leave unturned? When I read such stories when he was an infant, it horrified me, and here I was dealing with all of it. Despite my very best efforts, my son's profile had turned out remarkably different than the image I set forth for him in my mind.

He is an adorable, funny, sweet, loving little boy who suffers from debilitating mood swings, self-injury, aggres-

Closet, continued on page 3



Ellie

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Volume 35, Number 1 ~ January-February 2010 ~ Our 35th Year of Publication

PWSA (USA) Statistical Medical Overview

2nd Survey Family Reporting

By Janalee Heinemann, Director of Research & Medical Affairs and Barbara McManus, Director of Family Support & Database Coordinator

As most of you are aware, our goal with our two surveys is to give PWS practitioners and researchers a glimpse of the medical issues and research opportunities. We have shared with you some of the results of both surveys, and below is more of the data from the PWSA (USA) second survey. The ages of the participants range from infancy to 67 years. Not all responded to every question.

After distributing the first survey, the need to ask additional questions became apparent. In June of 2008, PWSA (USA) offered the second survey only to those who had completed the first survey. It was not mailed, but e-mailed to those who had e-mail addresses on file. Only 279 responded to this second survey. We are in the process of mailing survey #2 to all in survey #1 in the near future. If you have not filled out survey #1, we would be grateful if you do so by going to our web site (www.pwsausa.org/population) or calling 800-926-4797. The following is just a sample of a few of the responses:

Respiratory concerns = 279 Respondents

- 43 Asthma (15.41%)
- 47 Lung infections, Bronchitis or Pneumonia (16.90%)
- 35 on c-pap or bi-pap (12.54%)
- 66 problems with aspiration as an infant (17.41%)
- 74 Oxygen (26.52%), 42 Respirator (15.05%), 3 Tracheotomy (1.07%)
- 101 Sleep problems (36.20%)

Educational placement:

They were to mark if their child ever had placements (some may have had more than one).

- Inclusion Classroom (89)
- Special Ed Classroom (118)
- Combination of Special Ed and Inclusion (126)
- Special Ed School (48)
- One-on-one aide (86)

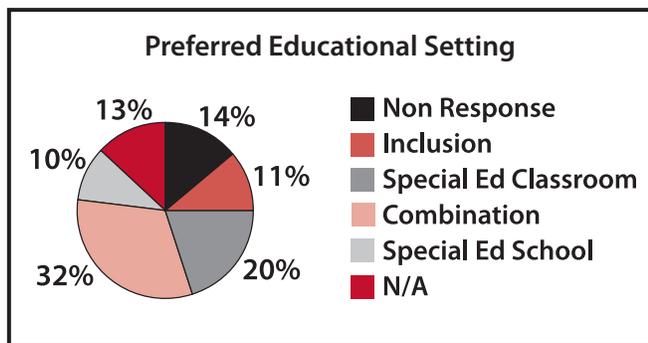
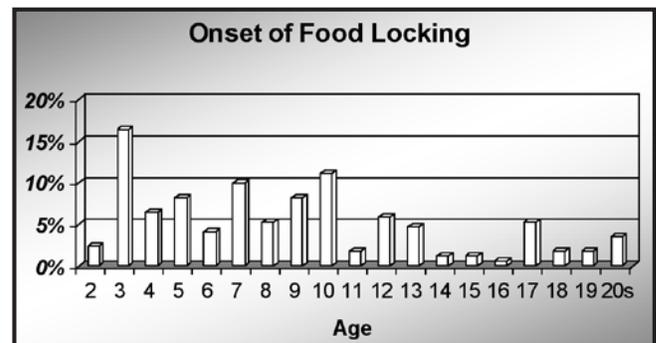
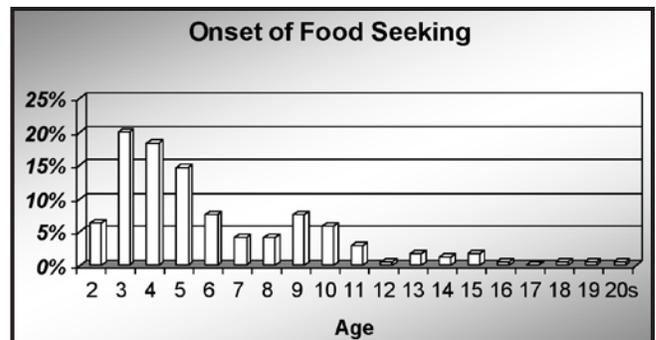
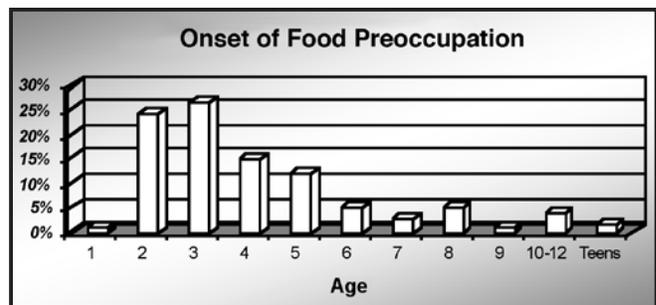
Living arrangements (ages 18 and up) = 87 respondents on those 18 and up:

- 60% still live at home with the parents
- 22% live in small supportive living homes with four or less in them
- 15% live in large group homes with more than 4 people in them
- 2 live in own apartment with supports

Food preoccupation/seeking/locking

The following charts show that every person with PWS is different. The onset of food preoccupation, seeking and locking occurred at various ages. Vertical on the graph represents the % of those responding.

Survey Overview, continued on page 8



Executive Director's View



Kim Weinberg

I'm sure that for my first column some people will expect a State of The Union address. However, I can only share with the PWSA community that I am surrounded by an outstanding professional staff that has welcomed me and shared their knowledge, stories and experience to help me learn about becoming part of the Prader-Willi syndrome family.

Janalee Heinemann, our director of Research and Medical Affairs, and Evan Farrar, director of Crisis Intervention, will join me on a management team where all areas of service are represented; we can draw from the years of experience we bring combined into one group. I am very impressed with the dedication of the staff and will now look towards the PWS family to challenge me, the staff, volunteers and the board of directors to reach new benchmarks in service, dedication and research.

Our goal is to build a better, stronger and more efficient organization that reaches all of the PWSA community and that will be able to guarantee that all of our operational and programming directions are mission-based with our long-term planning in mind.

Last week I was in Palm Beach Gardens attending the PWS Classic that was chaired by Ira and Ronnie Levine, grandparents of Josie. I was lucky enough to meet some of our families and had a chance to really listen to their insights and have taken those words to heart. If you at any point in time would like a phone call or face-to-face meeting, I can promise that you will find me extremely accessible. I look forward to being allowed to share in your lives.

A handwritten signature in cursive script that reads "Kim Weinberg".

Closet, *continued from page 1*

sion, skin picking, destructive behaviors, OCD, extreme perseveration, severe motor delays, vision problems, severe food seeking, cognitive disabilities, and more. He cannot write his name legibly, is not toilet trained, and spends most of his time in a special ed classroom with constant 1:1 support. He has additional diagnoses of ADD, PDD-NOS, Oppositional Defiant Disorder, and Mood Disorder. Our road has been difficult and painful and not at all what I had pictured for him or for our family.

But, of course, life does go on. Once I pulled myself together, I looked at what I needed to do for my son now that I have this information. I shifted my focus toward how to address his issues rather than wasting energy on how we got to this point. I do everything I can to keep him safe. He must be watched constantly. He will eat toothpaste, inedible plants, pills, raw/spoiled food and, yes, trash. He even talks about food in his sleep. I thought that locking the refrigerator and pantry would be enough, but food preparation is a huge issue. No amount of talking, convincing, or motivators can stop him in his quest. Punishments and consequences have absolutely no effect.

Environmental controls and keeping him busy are effective, although not foolproof. I am careful not to punish him for taking food; if he does, it is because I have not provided absolute food security that Drs. Forster and Gourash discuss in their excellent DVD "Food, Behavior

and Beyond." Also, as I learned from other parents, if he gets punished for taking food, he may learn to lie about it, which can have dangerous consequences. I have found it better to foster honesty; then afterwards, crank up the vigilance and the locking mechanisms. I always thank my son for telling me that he took something. He often cries afterwards and says, "I hate myself!" I try to remember that he doesn't like being this way any more than I like it.

I sometimes feel that all the talk of a "new generation of kids" and the perception of "us vs. them" (older vs. younger, Deletion vs. UPD) can give a false sense of complacency to parents early on, so that if food or other issues do come up, we are caught unprepared, shocked and self-blaming. Many whose children are doing well attribute a large part to what the parents did to help their child. I applaud those parents for their efforts and am happy to hear the many successes of the New Generation. I believe that interventions are extremely important.

But it is also true that some families can do everything right and still have a less favorable outcome. I want families in those situations to know that they are not alone; that they are doing their very best with the circumstances they have been given; and that there are families out there who know and understand what they are going through. For better or worse, we all are dealt a different hand in life, even in the world of PWS. ■

~ Jennifer Kryzak, Cedarburg, Wisconsin

PWS Research Strategy Workshop a Success

By Janalee Heinemann

Director of Research and Medical Affairs

Theresa Strong--PWS parent, PhD, chairperson of the FPWR Scientific Advisory Board, and PWSA (USA) member--took on the task of juggling yet another role. She coordinated this first PWS Research Strategy Workshop, November 15-17th in Bethesda, Maryland. I had the pleasure of attending along with Jamie Bassel, PWSA(USA) board member, and several researchers on the PWSA (USA) advisory boards. Sixty-five scientists participated, from eight countries. Many were 'PWS researchers', but about a third was from outside the PWS field, which brought in some fresh perspectives. Also important was the attendance of NIH members. The format of the meeting encouraged a lot of interaction and discussion (similar to our international hyperphagia conference). The goal was to work through how best to move PWS research ahead.

The meeting was kicked off Sunday evening with a reception and two outstanding talks. Keegan Johnson (FPWR-Canada's president) led off by providing a powerful parent's perspective. I am sure he inspired everyone in the room. Francis Collins, the Director of the U.S. National Institutes of Health, then gave the keynote talk. We were all impressed that Theresa was able to get him for this meeting. He ended with the quote "Not failure, but low aim, is crime."



Francis Collins and Keegan Johnson

Day two (Monday) consisted of an overview of each of the five areas that the Workshop focused on: Emerging Clinical Issues in PWS (Dr. Driscoll), Obesity and Hypothalamic Function (Dr. O'Rahilly), Mental Health (Dr. Holland), Molecular Genetics (Dr. Francke) and Animal Models (Dr. Wevrick). Each of these presentations was designed to bring all of the participants up to date on recent research relevant to PWS and set the stage for the afternoon's discussions. In the afternoon, the participants broke into groups according to the five themes. At the end of the day each group had identified strengths, weaknesses, important research questions, and resources needed.

Tuesday was spent with the entire group back together. Each moderator of the breakout sessions gave a report on what their group came up with, and this was discussed as a larger group. The last two hours was devoted a final discussion of the most important research questions and resources needed to move the field of PWS research ahead. The organizers are currently preparing a report from the Workshop for publication.

The workshop was financially supported by the NIH (Office of Rare Diseases Research and NIDDK), FPWR, PWSA (USA), FPWR-Canada, and the Canadian Institutes of Health Research. We plan to do further collaborative efforts in the future, and want to commend Theresa for her outstanding efforts towards making a better future for our children who have Prader-Willi syndrome. ■

hCG and Undescended Testes

By Jennifer Miller, M.D.

University of Florida, Gainesville, Florida

hCG (human chorionic gonadotropin) can be used in boys with PWS with undescended testes to help bring the testes into the scrotal sac without surgery. In other boys with cryptorchidism (without PWS), it only has approximately a 30% success rate, but it seems to be more successful for boys with PWS.

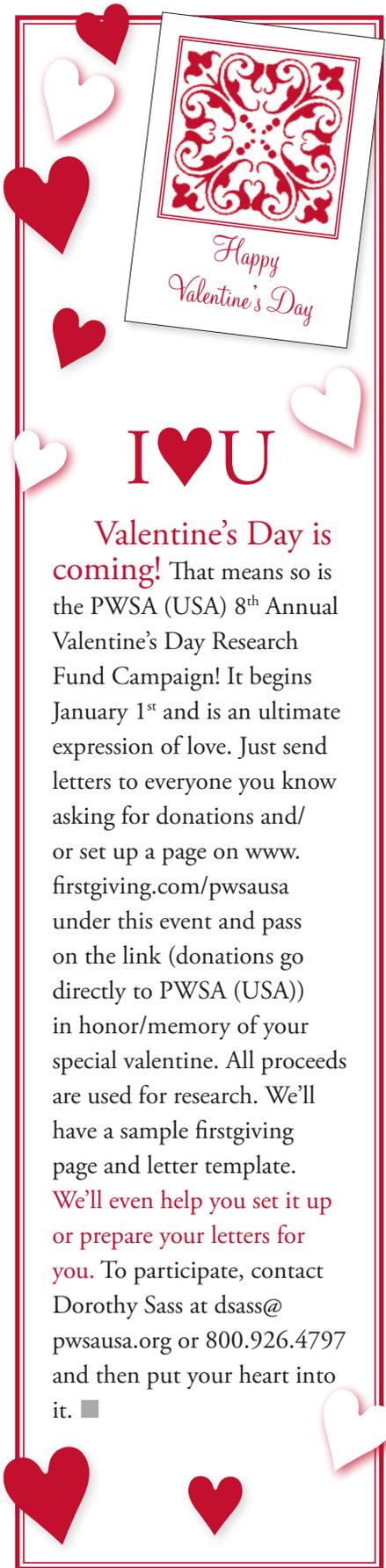
However, at this point the data on the long term success of hCG in boys with PWS and cryptorchidism is really lacking, so more data needs to be collected before any definitive statements can be made about the success of this treatment.

Our working hypothesis is that the success in boys with PWS may be because the mechanism of the undescended testes in PWS is due to hypotonia rather than whatever causes cryptorchidism to occur in boys without PWS.

Boys are typically treated with hCG if the testes are not completely descended by one year of age but are palpable in the inguinal canal. Testes that cannot be palpated by a physician are unlikely to respond to hCG treatment, and, therefore, surgery is typically necessary in that situation.

Thus far we have treated five boys with PWS with cryptorchidism with hCG, and 4 of 5 had success with testes descending into the scrotal sac and staying there (in other boys the high rate of failure is because the testes do not stay down after hCG). The one who did not have full success was only three months old the first time we treated him, so he is getting a second course this month (he is now closer to a year of age) to see if his testes come all the way down or if he needs surgery.

Another benefit of hCG for boys with PWS is that it often improves muscle mass. ■



I ♥ U

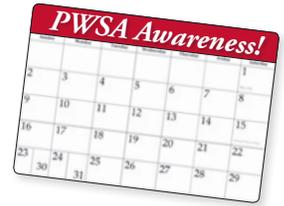
Valentine's Day is coming! That means so is the PWSA (USA) 8th Annual Valentine's Day Research Fund Campaign! It begins January 1st and is an ultimate expression of love. Just send letters to everyone you know asking for donations and/or set up a page on www.firstgiving.com/pwsausa under this event and pass on the link (donations go directly to PWSA (USA)) in honor/memory of your special valentine. All proceeds are used for research. We'll have a sample firstgiving page and letter template. **We'll even help you set it up or prepare your letters for you.** To participate, contact Dorothy Sass at dsass@pwsausa.org or 800.926.4797 and then put your heart into it. ■

"No one is useless in this world who lightens the burdens of another."

- Charles Dickens

PWS Awareness Month Is Coming!

This May, plan an event, education session, or anything else that will increase PWS awareness. The more who know about PWS the better! Call the office at 800-926-4797 if you need help or ideas. ■



Thank you to our 2009 grassroots supporters

Prader-Willi Syndrome Association (USA) is YOUR organization. However, like any non-profit, the extents to which we are able to provide services and fund research depend on the funds available. We have a generous Prader-Willi community of families and friends who have volunteered to offer financial support with grassroots fundraisers which have the added benefit of PWS awareness. We wish we had more space to tell you about each of these efforts, but listed below are the names of those who were not featured in earlier newsletters and who went the extra mile to see that PWSA (USA) continues its vital work. Thank you greatly to each and every person and their dedicated committees. It is YOU who makes this organization great!

- **Janice and David Agarwal**, Alex Fund, \$5,325 • **Brigid Amoroso**, 1st Annual Prader Palooza PWS Concert in honor of Angelina Amoroso, \$2,469 • **Fran Baehr**, PWS Bowling Fundraiser, \$3,000 • **Shandra Beer**, Emile's Fundraising Page, \$875 • **Christie and Kevin Bevacqua**, 6th Annual Jack M. Bevacqua Dinner Dance, \$20,229, NJ chapter • **Char Busch, Bev Delamos, Winnie Gators**, \$2,378 • **Shawna & Joyce Bush**, 3rd Annual Walk for PWS in honor of Carter Shingleton, \$2,714 • **Shannon Daale**, Rock & Roll 1/2 Marathon, \$20 • **Dominique DeLeage**, Putt for PWS, \$7,900 • **Barbara Emmons**, Arby's fundraiser, \$164 • **Bill Flemming, Maurice Fox, The Steck Family**, 4th Annual Golf Outing Benefiting PWSA (USA) and Light of Life Foundation, over \$3,200, • **Lynn Fuller**, Hay Day for PWS in honor of Emma Fuller, \$525 • **Cindy Galyean**, PWS Bowling Fundraiser, \$1,003 • **Larry Grundy & Town of Groton**, Tour De'Noank in honor of Camille Grundy, \$4,456 • **Karen Hamlin**, Ross Dress for Less Sample Sale, \$1,300 • **Haverfield**, Fundraiser in honor of Claudia Haverfield, \$70 • **Angela Hanson**, \$150 • **Jenna Huitink**, Fundraiser in honor of Anneka Kramer, \$160 • **Clint and Karla Hurdle**: Sixth Annual Golf Fore Prader-Willi Syndrome Golf Tournament in honor of Madison Hurdle, over \$85,000 national and CO chapter • **Jim Hurst**, \$1,850 • **Ellyn Jeager**, A Tasteful Evening of Wine, Cheese and Chocolate in honor of Lily Clare Schactman, \$3,773 • **Angela Krambeer**, School Awareness and Dylan's Special Day, \$280 • **Cheri McClane**, Julia's Awareness Month Page, \$1,020 • **Beth McLean**, PWS Night at the Mariners, \$3,580 • **Dorothy Morse**, PWS Yard Sale, \$730, research • **Vanessa Nedrick**, Jean Day, \$220 • **Ryan O'Sullivan**, 6th Marathon Run in honor of Josilyn Levine, over \$4,900 • **Nikki Oplie**, Fundraiser in honor of Grayson Oplie's 8th Birthday, \$360 • **Crystal Redner**, \$35 • **Sheila Richardson**, Longaberger Basket Bingo in honor of Adrian Richardson, \$570 • **Pam Santos**, 3rd Annual Jenna's Hope for a Cure, \$150 • **Megan Self**, Hudson Self's Birthday, \$1,050 • **Mandi Smith**, Hudson Smith's Birthday, \$365 • **Marsha Stalling**, Jean Day, \$500 • **The Little Farm, Thomas and Valerie Jornlid**, Charity Pumpkin Patch, \$842

The figures are net amounts. The list is of fundraisers with income from January through October 2009 not featured in earlier newsletters and not including Valentine's Day Research Campaign or Lose-A-Thon. We try to be accurate. Please alert us to any omissions or errors. Thank you. ■

The Important Cooperation: The Program on Prader-Willi Syndrome in Armenia

By *Albert Matevosyan M.D., Ph.D.*

Professor, Head of the Department of Medical Genetics, Yerevan State Medical University after M. Heratsi, Head of the Republic Center of Medical Genetics, President of the “Neurohereditary Diseases” Charity Association

There weren't registered and described cases of Prader-Willi Syndrome (PWS) in the Republic of Armenia as of 2007, but according to the literature data the prevalence of PWS in Armenia should be not less than 220 patients. Participation in the international conference on PWS in Romania in 2007 by invitation of IPWSO was the beginning of our steadfast attention to this problem in Armenia. My participation became possible due to the invitation of IPWSO.

Thanks to Pamela Eisen; the invaluable support and attention of Janalee Heinemann, PWSA (USA) Director of Research & Medical Affairs and IPWSO board member; constant operative information support from Giorgio Fornasier, IPWSO Executive Director; and Mark Greenberg, PWSA (USA) member who connected us to the Lency Fund Grant, the five-year research program on PWS has been developed and implemented in Armenia.

The purpose of the program is the study of the prevalence of Prader-Willi syndrome in Armenia, based on the increase of physicians' awareness and knowledge about PWS, its diagnosis and detection, as well as creation of database, a website, and development of medico-social assistance to patients with a mentioned pathology.

Thanks to the grant, a good demonstration and information base of association has been created. The mentioned base allows us to continue the accomplishment of the planned program and to conduct permanent informational and educational activities among physicians and population.

The association is periodically provided with literature by IPWSO. The literature is translated into Armenian and Russian and distributed among physicians and parents of patients. More than 13 information leaflets and booklets published by PWSA (USA) and IPWSO have been already translated.

Due to the program, city scientific practical conferences and seminars were conducted in 23 outpatient clinics and 5 medical centers of the Yerevan, during which booklets demonstration photo and video materials were presented. More than 700 physicians participated in the conferences. A great attention is paid also to the inclusion of corresponding information into students and residents curricula. More than 800 booklets on PWS in Armenian and Russian were developed and distributed among physicians and parents of patients.



*Above:
Dr. Matevosyan
with patient and her
parents*



*Discussing
the project*

Our experience shows that only cooperation between endocrinologists, neurologists, geneticists, pediatricians, general practitioners and other specialists can contribute to the detection and diagnostics of PWS. Permanent published information, meetings, seminars and created web site should contribute to the achievement of the mentioned goal. I am now working on an international rare disease conference with PWS as a focus group.

In conclusion, we would like to express our deep gratitude and to PWSA (USA) and IPWSO leaders for the continuous assistance and support in accomplishment of the program. ■

Timmy Story #1

Some of the young people in our Prader-Willi family create smiles as they go along through life. Timmy O'Leary, St. Louis, Missouri, has been famous for his exploits. This is also about the wonderful people who make life better for our children with PWS. Tune in next issue of the GV for Timmy Story #2, his birthday bash.

TIMMY O'LEARY, POLICE OFFICER

By Judy O'Leary, St. Louis, Missouri

Tim O'Leary, 39, has Prader-Willi syndrome and lives in a supportive group home. His dream has always been to become a police officer, if only for one day, and Judge Terry Burnet of Glendale made this possible by giving Tim the official Glendale police uniform and a promise to ride on patrol with one of his police officers. Tim's wish came true.

On July 18, 2009, in the City of Glendale, Court Clerk Lisa DeStefano asked Officer Matt Pappert if he would deputize Tim for one day for a two-hour cruise around Glendale. With permission of Chief Richard Black, the two of them set out to catch robbers and write tickets. Here is what happened on their two hour patrol spree - with justice on their minds.

Officer Matt explained to Tim about the gadgets, video camera, transmitter, and the rifle, as Tim sat motionless in the front seat of the patrol car. Tim was speechless (unusual for him), and he sat ever so quiet, taking in every word with amazement and excitement. When Officer Matt asked Tim to hold his hat, Tim was so honored that he held the hat as if it were a gift from God. Then they set out in their patrol car to protect society.

They first chased a speeding van (lights on and siren going) until the van pulled over and stopped. The lady said she was speeding because she just had her nails done. Tim said, "Give her a ticket." Matt agreed. Next they pulled over a car with one tail light out. Turned out the driver had a previous DWI and no proof of insurance. They agreed he should also be given a ticket. Next they put tickets on the wind shield of three illegally parked cars. After their shift was over, Tim wrote a ticket to Officer Matt - but his ticket was a sweet one. He gave Officer Matt his phone number and asked him to call anytime.

Judge Burnet said after Tim's patrol duty, "I think I have now created a monster because Tim actually believes he is an official police officer". Has Terry created a monster? **Absolutely – no doubt about it!**

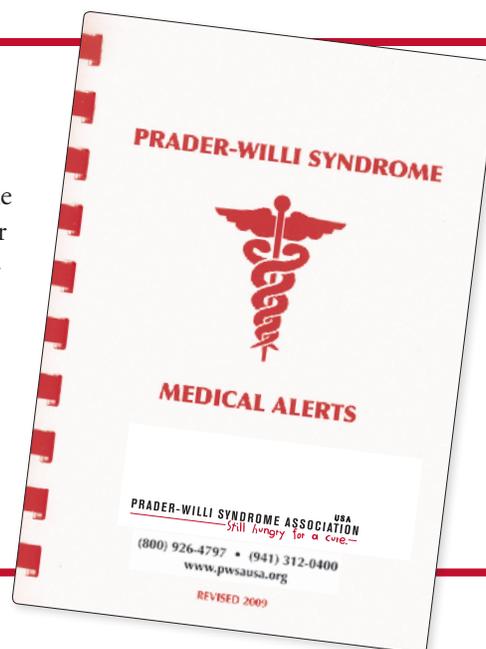
A special thank you to the Glendale Police Department, St. Louis, Missouri, for making this happen for my son. It is a day he will never, ever forget. As for myself, my grandfather was killed in the line-of-duty so I realize the unexpected danger faced daily by those serving to protect us. May God bless you all. ■



Police Officer Matt Pappert, Glendale Police Department, and Timmy O'Leary (right)

Medical Alert Booklet – Revised

Due to the new information on central adrenal insufficiency, the new growth hormone consensus statement, and a few other minor changes, we have revised our little Medical Alert booklet. We recommend that all parents and caregivers of a child or adult who has Prader-Willi syndrome have it with them at all times. The emergency room can be a dangerous place for those who have PWS, due to lack of knowledge of ER staff. This small booklet, which can be kept in a purse or glove compartment of a car, gives the essential information needed. To order it, go to www.pwsausa.org or call 800-926-4797. ■



Survey Overview, continued from page 2

Alternative Medications

The second survey asked questions about CoQ10, Carnitine, and Fish Oil.

CoQ10

- 44 currently using
- 47 discontinued using
- 149 had never used it

Satisfaction

- 24 very satisfied
- 25 somewhat satisfied
- 10 somewhat unsatisfied
- 14 were unsatisfied

Fish Oil

- 71 currently using
- 22 discontinued using
- 150 had never used it

Satisfaction

- 30 very satisfied
- 22 somewhat satisfied
- 6 somewhat unsatisfied
- none were unsatisfied

Carnitine

- 24 currently using
- 15 discontinued using
- 209 had never used it

Satisfaction

- 10 very satisfied
 - 15 somewhat satisfied
 - 3 somewhat unsatisfied
 - 1 was unsatisfied
-

Royce Legislation Establishes National Prader-Willi Syndrome Awareness Month

WASHINGTON, D.C. - Today, December 10, 2009 the House of Representatives passed H.Res.55, legislation offered by Rep. Ed Royce (R-CA) which establishes a National Prader-Willi Syndrome Awareness Month, and encourages continued federal research of this syndrome -- a recognized, common genetic cause of childhood obesity.

The resolution also recognized the importance of early diagnosis and the efforts and commitment of patient advocacy groups.

“With this legislation we can increase awareness of this genetic disorder among health care providers, pediatricians, parents, teachers, and communities. Additionally, we can begin to provide opportunities for fuller, more independent lives for those affected by this disease,” said Royce.

“House Resolution 55 is a great step toward a brighter future for those with PWS,” said Kim Weinberg, Executive Director, PWSA (USA). “The entire PWS community is appreciative of the efforts of Representatives Royce and Harman for their work and support.”

From The Home Front

A letter of thanks to benefactors of the Crisis Fund who prefer to remain anonymous

To the Dear People Who Care!

I've been told you are here for us. I've been told you send monetary gifts. I'm to understand your heart is full of love. You have been touched by someone with Prader-Willi syndrome. I know this is true; I know this because your gifts of money and love have touched our life! Your heart full of love has filled our painful hearts so that we can love again.

In October of 2001, we were blessed with a wonderful surprise named Austin. Little did we know of the journey on which we were about to embark. We fought and we struggled to get all the help we could for our son who was diagnosed with this strange disorder called Prader-Willi syndrome. Just how intimate our relationship would be...no one knew except for those who walked the journey before us.

As Austin approached 7 years old, some of the over-bearing attributes of PWS began to show themselves. We needed help desperately!! We were very thankful that we had a relationship with the national organization. This is where we were so fortunate to meet Evan Farrar. In times of total chaos and desperation, he was able to bring some sanity to our life. This gave

us the strength to help Austin. With each conversation we felt a renewed sense of empowerment.

Our struggle with the school was very apparent. Their lack of understanding and education disturbed Austin's balance. The desperation grew and grew. Evan put us in touch with Mary K. Ziccardi. Again, we were in


*"what we do know is
that someone with PWS
touched your life so
profoundly that you so
graciously gave to others
touched by the
same syndrome."*


the path of someone who knew of our struggle. She and Evan were people who could place all the pieces so that we could make some sense of what was happening.

Evan and Mary K. took part in many teleconferences with the school staff. Over and over we had conferences to help the educators to under-

stand the steps to take to help our son. Eventually, with a lot of hard work, the township "got the picture" and Austin was sent to the appropriate school. Mary K. came to our state of Virginia and assisted in the behavioral, physical and emotional support of our son in the school system and at home.

This new school welcomed her wealth of knowledge and used every bit of it.

Because of your gracious gift and loving heart, Evan and Mary K. were able to help our family in ways that will never be done justice with a single thank you. Your gift that enables Mary K. to physically stand alongside staff to educate them is invaluable. The actual presence of an authority in the school and in the home speaks volumes!! Our family is forever indebted to your family for its loving support.

We are pleased to say that Austin is thriving in his enriched school environment. He is understood, loved and taught in a nonjudgmental place. Our family has a better understanding of how to help Austin. Thank you from the bottom of our hearts. We don't know your name, your face, or your story...what we do know is that someone with PWS touched your life so profoundly that you so graciously gave to others touched by the same syndrome. We want you to know that your gift touches so many in such positive ways. Again, thank you! ■



My daughter Sierra, age 6, had a blood test a month ago to check for Central Adrenal Insufficiency. Two weeks later she was sick with fever and sore throat so we were off to the doctor again. In the waiting room she asked if they were going to take blood from her arm again. I told her no but they might do a finger prick to check her blood count. She said "I don't want the finger clicker (as she calls it)!" I explained that they need to take the blood to find out why she is sick. Her sweet response was "But I not sick in the hand, I sick in the head."

~ Cathy Truax
Dacula, Georgia

Best Practices for the Employee with Prader-Willi Syndrome

By Barb Dorn, RN, Consultant on Prader-Willi Syndrome
and Leslie Hall, MS, CRC Vocational Rehabilitation Counselor

Employers across the nation are taking steps to encourage healthy choices in their employees. There is talk of tax breaks for employers who have wellness programs. Employees may be rewarded with lower health insurance premiums. Low cost, healthy activities such as exercise opportunities, walking groups, smoking cessation programs and weight loss meetings are being included in the work day of many employees.

This article highlights simple, inexpensive ways to include health, wellness and socialization strategies for the person with Prader-Willi syndrome in the work setting. These modifications in their work day can result in a motivated, productive employee.

Social Development

Work environments are often social environments. Talking with co-workers and participating in social activities can be the most gratifying aspects in stressful jobs. Often what people love most about their jobs are the people they work with. Social involvement and social skills coaching can be an important component for the employee with PWS.

Many adults with PWS need social skills training and coaching in the work environment. People with PWS are often very social; however, they lack the skills of knowing the appropriate time, topics and place in which to engage in work place conversations. Include planned interactions.

Exercise and Movement

Exercise and movement are activities that many of us take for granted. Because people with PWS require constant food security and supervision, they have limited opportunities to freely move about. Many have sedentary job duties and sit for long periods of time. Daytime sleepiness is common. Those with limited activity often face extra challenges in staying alert and remaining productive. Inactivity can contribute to impaired circulation, resulting in swollen feet and ankles.

Including activity and movement can help keep employees with PWS awake, alert and stimulate blood flow. Depending on the venue, vocational staff can be quite creative. Making it fun will increase productivity and make coming to work more pleasurable. Expand the route to the time clock; find alternative routes to hang up coats; and store personal items in another location. Schedule hourly breaks that include exercise or movement. Take short walks. Create a walking club. Play music using an iPod device to make the walk more pleasant (and less disruptive to other

employees). Use a pedometer; set daily “step goals”; make a chart and provide rewards when personal goals are met. Rotate work stations. Use “geocaching”- a technological game which uses portable GPS to find an item which has been programmed into the GPS system (Google “geocaching” for more information). This can be tried with people with varying ability levels and can be done as a group or individually.

Workstation Accommodations

Simple changes in a person’s workstation can prevent problems with circulation, muscle and joints. The height of a table or desk should be adapted to minimize strain on shoulder, neck and hand joints. Since many people with PWS have poor muscle tone in their trunk area, their chair and/or table should be adjusted for proper height. This decreases muscle fatigue and injury. It can also lower the risk of circulation problems. Simple measures to assure that feet are resting on the floor, a stool or even an old telephone book can prevent feet from dangling in mid-air and enhance circulation. Ergonomic adaptations should be made for all employees who perform repetitive job tasks to prevent neck and shoulder problems. It may help avert carpal tunnel syndrome, a condition that has been attributed to performing repetitive hand maneuvers at an angle that causes stress to hand tendons.

Food, Fluids, and Nutrition

Close attention to food, fluids and nutrition is imperative. Food is a focal point in many work places. Potlucks, birthday treats and/or social gatherings are not uncommon during and after business hours. These events often improve morale and encourage camaraderie with colleagues. Planning and use of good nutritional choices can make these events inclusive for employees with PWS. Some ideas include:

- Educate fellow employees about PWS; ask for their help in making social events inclusive for the employee with PWS.
- Utilize low calorie foods and/or beverages.
- Choose 1 day a month to celebrate all birthdays in that month.
- Use low-calorie mini-cupcakes (100-calorie varieties), unsweetened flavored coffee or other low-calorie beverages.
- Focus on the party atmosphere (not just the food). Use hats, decorations and music!

- Encourage soup and/or salad potlucks or menus where calories are pre-planned. With advance planning, calories can be adjusted so the employee with PWS can participate.
- Plan special events or outings on Fridays - TGIF. We all look forward to the end of a work week – persons with PWS are no exception. TGIF benefits everyone's morale.
- Celebrate a holiday that falls in that month (if there isn't one – make one up).
- Host a special movie event.
- Honor an employee/employer appreciation day.
- Support a local athletic team (Brewers, Packers...).
- Sponsor a mid-winter beach day (wear Hawaiian shirts, sunglasses) for the final hour of the work day.

Fluids and hydration should be encouraged and dispensed in the work place. Water is one of our bodies' most important nutrients. It helps minimize thick saliva and crusting often seen on the sides of the mouths of persons with PWS and prevents cavities. It prevents constipation, improves skin, and maximizes kidney function. Persons with PWS often do not drink enough water. Moderation is key. An excessive intake of fluids can cause water intoxication, a serious health problem. Under-hydration is more common. More choices of flavored water are available, some now fortified with vitamins and nutrients. Make sure vending machines include these options.

Incentives

We all respond to incentives and motivational strategies. Incentives, whether financial or acknowledgement, help us to feel successful and appreciated. Bonuses or work-

ing overtime typically result in larger paychecks. Many people with PWS are visual learners and do best when outcomes are visual, concrete and measurable. Many benefit from low-cost incentives.

Acquiring Other Skills

During our typical work day we learn more than job tasks. Cooperation, team work and socialization are other important skills. People with PWS often have significant deficits in these areas. The work environment can be a place to learn and expand these skills. Learning ways to appropriately share and exhibit emotions aids the acceptance of the employee with PWS by co-workers.

Many employees with PWS face challenges in handling frustration and change and have a life-long need to learn to manage their emotional responses. Many learn to do this when change is predictable. Change should be foreshadowed and/or planned for. Provide structured learning opportunities so employees can learn and practice what to say or do when faced with a new or unplanned change. Organize and group similar work tasks together, e.g., schedule all clerical tasks in the morning and cleaning tasks in the afternoon. Provide encouragement and praise.

Health, wellness and socialization are all important components that should be included in the work day for all employees, especially those with PWS. Many simple opportunities exist for these employees to be successful in their work setting. ■

Production, printing, and mailing of this newsletter was underwritten by a generous grant from Eastside High School in Greenville, SC.

Can a person with PWS work and maintain SSI benefits?

The answer is yes because the Supplemental Security Income (SSI) program has several incentives available to encourage people on SSI to work and earn income without jeopardizing eligibility for benefits. To learn more about SSI work incentives visit

<http://www.ssa.gov/disabilityresearch/wi/generalinfo.htm>

Utilizing these incentives can help a person with PWS enjoy the sense of purpose, inclusion, and accomplishment employment provides. If you have questions about these incentives, or would like direction on who to contact in your community to learn more about the SSI work incentive program, please contact Evan Farrar, Crisis Intervention Counselor, at efarrar@pwsausa.org or 800-926-4797. ■

...help a person with PWS enjoy the sense of purpose, inclusion, and accomplishment employment provides.

Professional Providers Advisory Board – Budget Cuts and Advocacy

By *Steve Drago, Associate Director*
Arc of Alachua County

Advocacy groups around the country are mobilizing to fight budget cuts resulting from the financial crisis in this country. Everywhere battles are being waged by people with disabilities and their representatives to stop whittling away at funding for the most vulnerable citizens of our country.

Budget cuts for the individuals represented on the PWSA (USA) Professional Providers Advisory Board (PPAB) are so much more than just business decisions. We at The Arc of Alachua County in Florida represent 250 families; many of the provider agencies on the PPAB are equal or greater in size. We are home, friend and fiscal representative for many of these people. Imagine having to say “no” when you know “yes” is the right answer on this scale. We are faced with closing people’s homes, laying off trusted friends and staff and ultimately choosing to not provide a support to someone because we can’t afford to lose any more.

So what do we do about it? Professional providers are responding as they always have-- with creative, energetic and thoughtful plans. We have to make sure our people are heard. We have to tell their stories to our representatives. This is being done in a variety of ways, including direct visits to congressional representatives, letter writing, e-mailing and faxing personal appeals to stop the cuts. Your local advocacy agencies can help you in this effort. Every letter or e-mail represents a potential vote.

Belt tightening, a necessary survival skill in this environment, is an exercise at which we have all gotten very good. We have to operate our business on less revenue without affecting the health or safety of the people we are caring for. Every decision has to be reviewed with those two factors as the primary determinant. Is it still safe, and will it affect the health of the people we care for?

Non-profit agencies can fundraise, but this is often futile in this type of crisis. Grants are difficult and time-consuming but well worth the effort. We are seeing an increased opportunity for grants now, but the competition is fierce.

Self-sustaining enterprises are another option. We are really talking about diversifying revenue sources and decreasing dependence on government funding. Many support agencies operate on as high as 90% funding from federal and state governments. Making and selling products

and services that the community will support helps create a new revenue stream. I have even heard of non-profits opening used car dealerships to sell donated refurbished vehicles as an idea for new revenue. No idea should be discarded.

**So, when anyone asks
“What can we do about
funding cuts?”
focus on these
three areas:**

- 1) advocacy,**
- 2) belt-tightening, and**
- 3) developing new revenue sources.**

Apply your expertise to helping your agency, or the agency that serves your family member, to come up with some creative solutions.

My fellow providers do not want to have to say “no”. We are in this business because we care. We care about the lives of the people we serve and about providing the best quality supports that we can. Together we are much stronger than we are individually, so share your talents, support, and ideas with a provider near you. ■

UPCOMING PWSA (USA) WEBINAR - SAVE THE DATE

**Sunday, February 28, 2010
7:00 p.m. EST**

We are pleased to announce the first in our
webinar series for 2010.

“An Overview of Prader-Willi syndrome”
will be presented by Dr. Suzanne Cassidy.

Dr. Cassidy is the Director and Professor of
Genetics and Pediatrics at
U.C.I. Medical Center, Orange, CA,
and a member of PWSA (USA)’s
Scientific Advisory Board.

This webinar is geared specifically to
parents of newly-diagnosed children.

Please visit www.pwsausa.org
for additional details and
registration information.

Counselors Corner

Keeping Children Safe in School

On December 10, 2009, U.S. Representatives George Miller (D-CA) and Cathy McMorris Rodgers (R-WA) introduced H.R. 4247: the **Preventing Harmful Restraint and Seclusion in Schools Act**. According to the House Committee on Education and Labor, the goal of the legislation is to prevent and reduce inappropriate restraint and seclusion by establishing minimum safety standards in schools, similar to protections already in place in hospitals and non-medical community-based facilities. For more information about HR 4247, visit: <http://edlabor.house.gov/blog/2009/12/preventing-harmful-restraint-a.shtml> U.S. Senator Chris Dodd (D-CT) has introduced companion legislation in the Senate.

H.R. 4247 has received the strong endorsement of many disability rights groups including the National Disability Rights Network, The Arc of the United States, and the Council of Parent Attorneys and Advocates (COPAA). Alice Nelson, the Chair of the COPAA Board explains, "It is essential to protect each student's right to be free from abuse in the school house." We agree! As we've discussed in recent issues of the *Gathered View*, students with PWS are among those often targeted in school settings for improper use of restraint and seclusion. So we strongly urge members and friends of PWSA (USA) to contact their local congressional representatives to express support for H.R. 4247 so that all children - including those living with PWS - will be safe at school. ■

~ Evan Farrar

Crisis Intervention Counselor

Family Support Services

Barbara McManus, Director of Family Support Services at PWSA (USA), has a plan. "If everyone in every corner of every state were communicating with others, solutions would follow."

PWSA (USA) receives calls every day about a range of issues, including need for placement, school IEP assistance, Medicaid waiver, physician referrals and state legislation concerns, all of which are dependent on



Barbara McManus

the state, county or location of the parents. A state chapter might be able to supply the help needed--but not every state has a chapter, and not every chapter has the resources to help every concern a parent may have.

"Sometimes," says Barbara, "we need to 'create' services where there are no services available, or we might need to join forces to make change that occurs at the state level. Communication between all the families is the starting point. Communication is vital for success. With or without a chapter, we need to join together."

Barbara is creating Yahoo! support groups for state-specific communications. Recently E-support groups were created for Florida, Georgia, Tennessee, Oregon, Washington, Massachusetts, Illinois, Idaho, Nebraska, and others are being created every day.

The e-mail groups can share state-specific resources, work toward changing state eligibility for services, share IEP solutions, identify physicians who "get it" and provide information about when the next groups are going to meet and where. In addition, families who may not live far from each other may connect.

If you live in a state that needs a E-support group and does not have one listed at <http://www.pwsausa.org/links/chapter.htm>, please call Barbara at 800-926-4797. ■

REM Ohio Gets Award

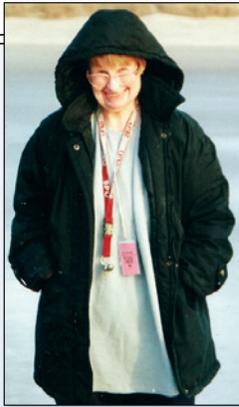
Four employees in the Cleveland office of REM Ohio, a provider of services to adults with developmental disabilities, received the **Outstanding Team Award** from the Ohio Provider Resource Association for their work with adults with Prader-Willi Syndrome. This included two active PWSA (USA) members Mary K. Ziccardi, area administrator, and Laura Orozco, program director. ■

Sharing Knowledge and Support

Christine Gallant, Director of Marketing & Training for Latham Centers, Inc., a residential provider in Brewster, Massachusetts, reported that 108 people attended the Prader-Willi syndrome conference held Oct. 16-17 on Cape Cod—in spite of a Nor'easter which blew in from the sea. The conference, sponsored by Latham Centers, Advocates Inc. and the Prader-Willi Association of New England, featured speakers including Dr. Janice Forster, Dr. Linda Gourash, and Dr. B. J. Goff on topics relating to the treatment, care and support of individuals with PWS.

In addition to the presentations, attendees had opportunities to network with other parents and professionals and to ask pertinent questions to a six-member panel on Living with My Child in the Community and Transition Challenges for Families.

The conference was deemed a success, not only by the organizations who sponsored it, but by the attendees who are already asking...when is the next one? ■



We Remember

Alice Laura Carney died Oct. 3, 2009, at age 67. She received touching tributes from her best friend, Malee Shay, and from her cousin Jan Pender, whom she visited frequently in Arizona.

Malee says: *I have had a massage therapy business in Woodinville, Washington, for 21 years. I was blessed to first meet Alice on April 26, 2005, her initial appointment. How was I to know then that Alice would change my life and teach me so many lessons? We fast became the closest of friends...Her compassion, humor, generosity, keen insight and true friendship made me take a hard look at some of the other "friends" in my life...She was one of a kind, a heart of gold, intuitive, intelligent, optimistic in the face of adversity, giving, caring, loving.*

Her presence will never fade, it will only grow stronger.

Jan says: *She had this contagious little giggle which would fill the room and make everyone smile; the kind of laugh that came from the belly, yet warmed the heart. That laugh is one of the things I will miss the most. That and her sense of humor, her innate ability to sense the good in people, and her simple honesty. You could never pull anything over on Alice. She had an incredibly sharp memory, a sensitive nature, and a compassion for animals that was matched by no other. She loved any and all animals...She was indeed a special person who touched my soul and warmed my heart. I will be forever grateful that I was given the opportunity to know her, to love her, to be touched by her sweet smile and gentle goodness. Alice has escaped this earth, but the footprints she has left behind are entrenched for eternity upon those of us who were fortunate to have known her.*

Contributions

Thank you for Contributions in October and November 2009

We try to be accurate in recognizing contributions, and apologize for any errors or omissions. If you notice an error, please tell us.

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Prader-Willi syndrome (PWS) is a birth defect identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition, which affects appetite, growth, metabolism, cognitive functioning and behavior. Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions. To make a donation, go to www.pwsausa.org/donate



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PRADER-WILLI SYNDROME ASSOCIATION
—Still hungry for a cure.—

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Our Mission: PWSA (USA) is an organization of families and professionals working together to promote and fund research, provide education, and offer support to enhance the quality of life of those affected by Prader-Willi syndrome.

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E-mail Support Groups:

We sponsor nine groups to share information.

Go to: www.pwsausa.org/egroups

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