



The

# Gathered View

February 1996  
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National Newsletter of the Prader-Willi Syndrome Association (USA)

## President's Message

### The Next Step to the 'New Horizon'

*Jerry R. Park, President, PWSA (USA)*

It is time to begin our effort to focus on Awareness Week 1996. As co-directors of this event, Board Member Gail Overton and I intend to build on last year's success in Washington and continue to make the event very important in the growth of PWSA in your state.

We and the board of directors have developed goals for this year that will solidify the partnership of National and the state chapters. National success depends on your success at the state level, and Awareness Week is the cornerstone. The Awareness Week theme will continue to be "A New Horizon for Prader-Willi Syndrome," but our 1996 focus is awareness at the state level through your legislature and membership recruitment.

As appropriations begin to flow from Washington to the states through your legislators, block grants, or a form of State Health Care Alliance/Authority, you need to know who to contact in your state. Together, we are going to focus on your capital, your legislators, and to raise public awareness in your government. We cannot be passive and assume that funds will always be available for your child and his or her provider, medical expenses, and specialized schooling. We must go forward as Aware Advocates!

The National Association needs state chapters for the expansion of funding through awareness. Our fund-raising efforts this year take on greater significance, and planning is a key element in that process. Our goal is to raise \$25,000 for the National Association through a 60/40 split, with chapters keeping 60 percent of the funds they raise.

In the final analysis, what should Awareness Week represent to all of us? And what should we expect? Each of us wants to contribute, and Awareness Week gives us that opportunity. We all want to tell the world so they will understand our situation and contribute generously, and we have that opportunity. We need the medical community to understand Prader-Willi so the next birth will be quickly identified, and the family can benefit from early intervention.

We all can take a great deal of pride in our accomplishments during the first Awareness Week, but let's be able to look back on Spring of 1996 and say we took the next step toward "A New Horizon for Prader-Willi Syndrome."

### PWS Awareness Week

April 29–May 4  
1996

A New Horizon for  
Prader-Willi  
Syndrome

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## Out of the Office

by Russ Myler, Executive Director

Our membership application form and the membership renewal card include a space for volunteering yourself for the "Sharing List." This vital component of the life of the Association has made a major difference in the lives of so many.

The Sharing List means you will give your support to another family learning to live with the syndrome, just as you are. This integral part of the family support network does not require your being a counselor or therapist, just a friend facing many of the same issues. Many of you have chosen not to be on the sharing list because you feel you don't know enough to be on the list. Believe me, as a parent you know better than anyone what kind of support is needed. This list is designed to help parents support parents, relatives to support relatives.

This year more than 130 families with a child diagnosed with Prader-Willi syndrome discovered PWSA (USA). Of those, 106 have chosen to join the Association. That means that almost 10 percent of our parent members are new to us as well as to the syndrome. All of us know just how much these persons need what PWSA (USA) has to offer—support and information.

The Sharing List members need you to help in sharing experiences, passing along tips about what has worked (or not) for you, and providing support and strength to others.

Next time you renew your membership, please consider checking the "Sharing List" box. Our new members could use your help.

### Nominations for Board of Directors

For the July 1996 elections, the Nominating Committee requests that the names of members interested in, or recommended for, a seat on the PWSA (USA) board of directors be submitted to the committee no later than April 29, 1996. Recommendations should include a brief description of the member's qualifications to serve on the board. Please mail, fax, or e-mail recommendations to the attention of the Nominating Committee Chair, c/o PWSA (USA) at the address or fax number shown below.

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

**Editors:** Linda Keder, Silver Spring, Md.  
Lota Mitchell, M.S.W., Pittsburgh, Pa.

Communications regarding *The Gathered View* or PWSA membership should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or (314) 962-7644 in the St. Louis area. Fax (314) 962-7869. E-mail: pwsa usa@aol.com.



# MEET ME WHERE THE LIGHTS ARE SHINING

## 18th Annual PWSA Conference July 18-20, 1996

### Wednesday, July 17

Scientific Day  
Chapter Presidents' Meeting  
Conference Registration  
Evening Social

### Thurs.-Sat., July 18-20

Conference Sessions  
Service Providers' Seminar  
General Membership Meeting

The lights are shining brightly as we confirm our plans for the 18th Annual PWSA-USA National Conference in St. Louis, July 18-20. We have added some new topics and made a few schedule changes which will be interesting to our first timers as well as veteran attendees.

Plan to arrive early so you can take advantage of a St. Louis tour offered by Regency Travel. You will be able to visit the famous St. Louis Gateway Arch and a bus tour of other sights around town. More information will be in your conference packet.

The Youth and Adult Activity Program (YAAP) will be divided into age categories. Thursday provides a seminar format for our adults with PWS and different activities for the younger groups. The YAAP will travel to the Magic House Thursday evening, while the parents will have an opportunity to try their luck at the St. Charles Casino. Both of these activities are free of charge, but preregistration is required. Friday, the YAAP will visit area sights of interest to all ages. As in the past, we will provide child care for the infant-to-age-5 group.

A primary change to this year's agenda is the Service Providers' Seminar. It will be held on Thursday instead of Wednesday. This is separate from the general conference schedule.

The conference packet is scheduled to be mailed in early March. You can make your hotel reservations now by calling Pat Mann, Regency Travel, 1-800-784-7581 or 314-725-7581.

The Missouri chapter looks forward to being your host this year and hopes you are planning to attend. If you have any questions, feel free to contact either of the co-chairs: Paula Kollarik, 314-523-7350, ext. 7401 (work), or Jerri Evetts, 314-391-7118 (home).

### ***Conference Grants Available***

PWSA (USA) offers grants to families who want to attend the national conference but cannot afford the expense. Application should be made by letter to the Executive Director, PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326, and must be received at the national office by **April 29** to be considered. Decisions on grant applications are made by PWSA's Conference Grants Committee.

### ***Grant application letters must include:***

1. the size of your family and age(s) of your child(ren);
2. an indication of your income and expenses;
3. a brief summary of difficulties your family is experiencing in dealing with PWS;
4. whether your family would need all conference expenses paid or only some expenses (e.g., just transportation or lodging); and
5. whether anyone in your family has attended a previous PWSA national conference.



## A New Procedure for Tissue Donation to Support Research on Prader-Willi Syndrome

Several times in recent years, *The Gathered View* has told PWSA members of the need for human tissue donations from individuals with Prader-Willi syndrome to further the cause of PWS research. Brain tissue, in particular, is critical to researchers who are trying to learn why PWS causes dysfunction in the brain and whether new treatments might be developed. To be useful to researchers, brain tissue must be obtained *within hours* of a person's death, requiring a prompt decision from the family and a major coordination of effort.

Some families will find this difficult to contemplate, in the same way that some feel they could not consider donating organs for transplant when a loved one dies. However, other families find that such a donation gives greater meaning and purpose to the life of their loved one with PWS. When one such family tried to arrange a tissue donation last spring at the time of their child's death, it became clear to PWS researchers and the many others who became involved that a procedure was needed to simplify the process and reduce the burden on a grieving family.

In the months that followed, members of the PWSA Scientific Advisory Board developed such a procedure in conjunction with the Brain and Tissue Banks for Developmental Disorders, two centers that are funded by the National Institutes of Child Health and Human Development specifically to register donors and to collect, preserve, and disseminate tissue for research. PWSA's scientific advisors will assist families with the decision to donate, as needed, and will make recommendations regarding use of the PWS tissue in specific research projects.

### The Procedure in Brief

The Brain and Tissue Banks, located at the University of Maryland in Baltimore and the University of Miami in Florida, will preregister individuals with PWS whose families would consider making tissue donations. In addition to brain tissue, other bodily tissue can be helpful to PWS researchers and could be obtained, with the family's or individual's permission, at the time of a planned surgery or biopsy for medical reasons.

Both banks have 24-hour, toll-free phone numbers that families can use to get information and counseling about tissue donation and to arrange for tissue collection in advance of a medical procedure or in the event of death of the registered family member. Even if a family has not preregistered, an *immediate* call to the nearest tissue bank may make possible a tissue donation in the event of sudden death of the loved one with PWS. In general, the Maryland bank will serve donors in the northern half of the United States, and the Florida bank will serve the southern half. Families may call the banks directly, but those who are unsure which bank to call or who wish to speak with a PWSA scientific advisor first should call the office of David

Ledbetter, Ph.D., at the National Institutes of Health and speak with either Dr. Ledbetter or Ann C.M. Smith, M.A., a genetic counselor who is coordinating the procedure for PWSA.

### Some Reassurances

Tissue donation and the death of a loved one are not easy things to consider. Many questions may come to mind, most of which can be answered by a phone call to the Brain and Tissue Bank counselors or to Dr. Ledbetter's office. Families should be assured that, given the sensitive nature of their task, the Brain and Tissue Banks have set as their highest priority "the emotional and physical well-being of the families and individuals" with whom they interact. Families who call for information are not pressured to register. Time is taken to inform everyone involved of the purpose and process of tissue donation. Donor information is kept in strictest confidence. And registration is not an absolute commitment to make the donation; only the next of kin at the time of the person's death can give final permission for tissue retrieval.

### Key Telephone Numbers

*To obtain information about tissue donation and advance registration or to report the death or impending death of a family member with PWS:*

#### **Northern half of the United States** **1-800-847-1539**

Brain and Tissue Bank for Developmental Disorders  
Sally Wisniewski, B.A., Project Coordinator  
University of Maryland  
Department of Pediatrics, Rm. 10-035 BRB  
655 West Baltimore St.  
Baltimore, Maryland 21201-1559

#### **Southern half of the United States** **1-800-592-7246**

Brain and Tissue Bank for Developmental Disorders  
Elsa Robinson, R.N., Project Coordinator  
University of Miami  
Department of Neurology (D4-5), 708 The Gautier Bldg.  
1011 N.W. 15th St.  
Miami, Florida 33136

*For guidance on which bank to call or to speak with a PWSA scientific advisor:*

David Ledbetter, Ph.D., or Ann C.M. Smith, M.A., CGC  
National Institutes of Health  
Bethesda, Maryland  
(301) 402-2011



## **Alert to Parents and Caretakers of Individuals with PWS!**

### **You can help develop a valuable new tool for measuring effectiveness of treatments—The 'Prader-Willi Behavior Rating Form'**

Russell Gardner, Jr., M.D., a psychiatrist at the University of Texas Medical Branch in Galveston, wishes to evaluate therapeutic interventions in patients with PWS. Treatments may be either undervalued or overvalued unless systematic and scientific work to measure their performance is done in the PW population itself. To assist in doing this, Dr. Gardner has composed the 35-item *Prader-Willi Behavior Rating Form* with the help of Scott Raynaud, a psychologist from Texas Children's Hospital in Houston and Janice Forster, a psychiatrist from the Rehabilitation Institute of Pittsburgh.

The investigators have designed the questionnaire to measure typical behaviors of the syndrome, aiming at the behavior profile of the month just passed. Thus, when an intervention such as a medication is tried, the instrument should register any syndrome-related changes that occur.

Thanks to the cooperation of parents and caregivers at the Seattle meeting of the PWSA (USA) in July 1995 and those who make monthly visits to Texas Children's Hospital in Houston, 95 patients have been rated and a total of 162 questionnaires received. (Some patients were rated by two parents or caregivers, and some were rated at two points in time by the same person.) Results show the test to be internally reliable, but the researchers still need many more ratings to check the reliability of the instrument's subcomponents.

*People who have already filled out the form don't need to respond to this further except to tell other parents or caregivers how simple the form is and urge them to participate.*

**If you answer Yes to the following questions, please let Dr. Gardner know that you wish to participate in this important research:**

- Are you the parent or other caregiver of a patient with PWS?
- Is the patient 6 or more years old?
- Are you in reasonably close contact with his or her behavior?
- Has this contact happened over the last month?
- Are you willing to answer 35 questions about the individual's behavior?

The investigators are sensitive to the confidentiality requirements of community facilities and stress that the actual name of the patient is *not* required—only the birthdate, sex, and a coded identifier to prevent inadvertent duplicate responses.

**Please contact Dr. Gardner by mail, phone, FAX or e-mail to request the Prader-Willi Behavior Rating Form.** If two parents or caregivers are willing to participate, please request two forms and indicate who will be completing them.

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Galveston, TX 77555-0428  
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FAX: (409) 772-6771  
E-mail: rgardner@utmb.edu

## **Scientific Day 1996**

PWSA has mailed information and the annual call for papers concerning the 11th Annual Scientific Day, July 17, 1996. The Scientific Day is devoted to the presentation of new research on Prader-Willi syndrome and is open to all interested professionals.

**If you know of any professionals who should be added to the mailing list for Scientific Day information, please call the national PWSA office at 1-800-926-4797.**

## **NY-New England Conference April 26–27, 1996**

The Prader-Willi Alliance of New York, Inc., and the Prader-Willi Syndrome Association of New England, Inc., will hold their 4th annual joint conference in Albany, N.Y., on Friday, April 26 and Saturday, April 27, 1996.

The conference will be held at "The Desmond" hotel, located at 660 Albany-Shaker Road, Albany, New York 12211.

Room costs are \$89 per night, and reservations may be made by calling (800) 448-3500.

Additional information about the conference and lower-cost rooms may be obtained by calling (800) 358-0682.



# Diary of a Placement

by Lota Mitchell, M.S.W.

## Before

**April 24, 1995:** 1:15 a.m. The phone rang, awakening me. A nice man (thank goodness!) said he had just put our daughter Julie on the trolley (two miles from our house) into Pittsburgh. She told him she was 25 and going to see her boyfriend (both true), but he, dubious, got enough information to find our number. At 2:00 a.m. I picked her up alone in downtown Pittsburgh.

**April 25:** I called her case manager, Kathy, to relate this latest escapade, as I have been doing for the past year to underline the need for residential placement. In the last episode two months ago she found an unlocked door at 5:00 a.m. and raided a neighbor's kitchen. The neighbor thought it was a burglar and called the police. When the policeman learned that what had been taken was yogurt, raisins, and two pieces of pizza, he asked: "Does Julie Mitchell live around here?" Why don't we put in a security system? Because she says she'll rip it out of the wall.

**April 27:** Kathy called back. There is no chance of placement in our county for another year. Even then there might not be a provider who's willing to take on such a "difficult diagnosis" (sounds like they finally got the picture). Would we be interested in Keystone, a provider in eastern Pennsylvania, 5½ hours away, which has a specialized program for PWS? Five and a half hours!! Her father and I were stunned.

**May 8:** I'm struggling with ambivalent feelings—the distance vs. my exhaustion with trying to keep her safe from food and now from the nocturnal wanderings. Empty candy wrappers under her pillow—how does she get them? Except for nighttime, she is supervised constantly. I have a philosophy that everything that happens to us is a process. We build up to an event or we adjust to one that's happened or both; nothing stands alone. I have been in a "chronic" (so to speak) process anticipating her entering a group home since she was 12. Now the process is "acute."

**May 13:** We visited Keystone. There are two houses for PWS situated on a lovely 73-acre campus near the Pocono mountains with a pond, wild geese who have moved in to raise a family, two swimming pools, and much open space. The staff, who seemed caring and knowledgeable, described a host of activities available to the residents—great for Julie, who always wants things to do. The residents have all lost weight. Julie liked it. On the trip home I mused I must treasure her time left at home. I thought of the good times together, the company she is for me, the help she provides, our nightly double solitaire games.

**May 14, Mother's Day:** Julie had a card and made gifts for me at craft night. The morning was great, but in the afternoon she became a PW crab. The good thoughts of

yesterday turned into wondering if I can stand it until she goes.

**May 15:** I called Kathy to go ahead with Julie entering Keystone. Some ambivalence remains, but there is more of the letting go, a feeling of relief that I won't have to maintain this vigilance forever, that I can turn over this huge responsibility, that there is at last light at the end of the tunnel.

**May 29:** Memorial Day Weekend, and a good one. Julie helped with everything—folding laundry, putting it away, cleaning up under the deck outside. She is to enter Keystone Labor Day weekend. I want August to be special, after she returns from eight weeks at Camp Sky Ranch in N.C.

**June 10:** I put her on the plane to N.C. with relief, so glad to see her go after an awful week which started with the issue of candy bags for the kids at our neighborhood block party. Julie does not have hour-long or even daylong tantrums; hers can last for days and days.

**July:** Friends at the PWSA national conference asked how I felt about Julie leaving home, and I tossed off blithely, "No problem! That week before camp took care of all my ambivalence!" However, we have received many pleasant letters from her, memory of the disastrous week has faded, and I look forward to her being home in August.

(Later I read a newspaper feature about parents imagining wonderful togetherness the last month before their kids go off to college—and how it seldom happens.) Occasionally I muse about myself. I've managed to maintain a fulltime, satisfying job, but often I've marveled at the freedom of my contemporaries whose children are grown. I'm not down to the "Get a life!" level, but I puzzle over what I will do with my new-found freedom.

**August 13:** Julie came home Aug. 4, and she was great—for four days. Then came the issue of taking a walk by herself when all the neighborhood garbage cans were at the curb for pickup, followed by another miserable week of sullenness, defiance, and taking off to who-knows-where and sneaking back in long after dark. If I had another year of this ahead of me, I don't think I could last. So much for the wonderful month of August.

**August 20:** I wonder if Julie is feeling some tension and anxiety underneath, even though she says she is excited and wants to go. This will be a big change for her, too. As we go from good days to bad days and back again, my ambivalence, which I am startled to find still with me, ebbs and flows, too. However, there's no ambivalence about the decision. I know I can no longer keep her safe from either food or the dangers of her night wanderings. It is instead a grieving which pops up when I least expect it.



**August 24:** While I was distracted, Julie polished off the rest of the Caesar salad tonight. I normally would have reacted, since I've battled so hard to keep her 4'9" body down to 112 pounds, but instead ... I shrugged. I find I am not nearly as careful about her food intake, knowing that this will shortly be taken over with much more control that I can possibly exert.

**Sept. 1:** Tomorrow is the Big Day. The week reminds me of the little girl with the curl in the middle of her forehead: "When she was good, she was very, very good, but when she was bad, she was horrid!" I have been an emotional pendulum, swinging wildly in response to her behaviors, at one moment wishing Sept. 2 would hurry, at another dreading its arrival.

## After

**Sept. 2:** When our van turned homeward, I tried to sort out my jumbled feelings. Only one was clearly defined, and it was hope—hope that Julie will be happy and contented in her new home into which she and her hamster, Brownie, seemed to settle so quickly. Tears welled up off and on, but never overflowed until I walked in my front door. Then they came in torrents. This is what we had looked forward to; I had no idea it would hit me so hard.

**Sept. 3:** The boulder of responsibility which has sat on my shoulders for so long is gone, but what is left feels today like emptiness, not freedom. I don't yet fit my new identity: "mother, retired." Even though I love my work, I

am like most women in that it does not define who I am. I'm certain I will come to enjoy this new life, but I also know that when any change comes, one must mourn What Was before one can fully participate in What Is. I am not ready yet to appreciate having the locks off the fridge and pantry and the sugar bowl in the middle of the breakfast table.

*I wonder if I would be feeling differently if Julie were on the other side of the county instead of the other side of a very wide state. I wonder if my feelings are like those of other mothers, and fathers, too, who have taken their child with PW to a home away from home. I wonder if those reading this who have had the experience would write about what it was like for them. This is my invitation to those of you who have, so that others who will someday go through it may be a little better prepared and know what to expect. What was it like for you?*



By the end of seven days I was indeed enjoying having no locks, being able to come and go as I wished, and not worrying about little house noises in the night because it wasn't Julie sneaking in or out. For several weeks I OD'd on my freedom and was out every night like a college kid out from under the parental thumb! In late October Julie came home for a weekend. I was delighted to see her, it was a pleasant three days—and it was fine with me when she went back. Julie was most happy to come home—and most happy to return to her new home. For all of us, the new life is good.

## A Note from Julie



Julie in front of her residence, "Aspen House," September 1995

My name is Julie Mitchell, and I have Prader-Willi syndrome. Like all the other ones do. My age is 25 years old. I used to live at home, going to work and going to school.

But now I live in this group home in Keystone which is near Scranton, Pa. That's kind of out in the country with no access to food. It's for Prader-Willi but a lot of other disabilities, too. We live on a big campus with log cabin houses all around it that we live in. There's a cafeteria for people that go to work on campus which you would call workshops. We dance in there, too, or have parties. There's an office with a nurse's office in it. Two lakes where they could go fishing and boating. We also have a lot of geese that hang around. They will go out in middle of the road. But they move out of the way. Different buildings you go to, have picnics there at picnic tables.

My house has seven Prader-Willi's in our group home. It's called Aspen. Six girls and one boy. [Note: There is another house called Spruce with all males, making a total of 16 residents with PWS.] Pam and Candace are my roommates. The other three girls are roommates. Jim has a room to himself so there's three bedrooms plus living room and dining room where we eat our meals. What I like about living here is I have people to play with, go places together, and do things together.

We play Spit, card games, board games, or whatever in evening. We do that with the staff. The staff takes us to the movies, to the mall, shopping, bowling on Fridays, the library, places for Halloween, K-Mart and WalMart to get supplies, or anywhere to have fun.

But the really best or two best things I like about it is that I have friends and staff to play with, go places with, and do things with. So we can be together and kept busy.





## Encouraging Words on Estrogen and Early Intervention

Robyn was diagnosed with PWS when she was 4 years, 9 months. Today, at age 19 years, 9 months, Robyn is 4'10" and maintains a weight of 117! This is partly due to the hard work of Devereux in New York, which carefully monitors her caloric intake and exercise. When she is home on vacation, I do not need to lock food since she has been used to limited food intake throughout her life. (A wise pediatrician told us to monitor her caloric intake as a toddler.)

In addition, Robyn began getting her period at age 18 with the help of low-dosage estrogen. A recent sonogram revealed normal-sized ovaries but a small uterus. During an endocrine evaluation, she produced no estrogen. This, along with a bone density study that revealed 35 percent bone loss at age 18 prompted the treatment with estrogen, which brought on a "period." She is currently being cycled with LoOrval and visits the gynecologist for regular pap smears. (She loves this doctor and was very cooperative, to my delight!)

An unexpected blessing that came along with the hormones was the development of breast tissue (AA cup) and a more womanly figure. Her self-esteem also gained a boost with the weight loss of 10 lbs. (I thought these pills would make her gain weight.)

Please share this information with others.

*Maxine Geller  
Baldwin, New York*

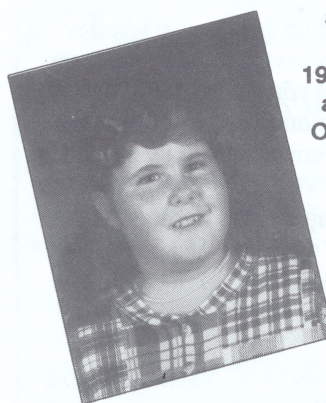
## Attention, Teachers!

Donna Jones, a teacher in northern Canada, wishes to communicate with other teachers of children with PWS. Donna teaches a Life Skills Resource Program and has a 7-year-old student with PWS, a boy named Sidney.

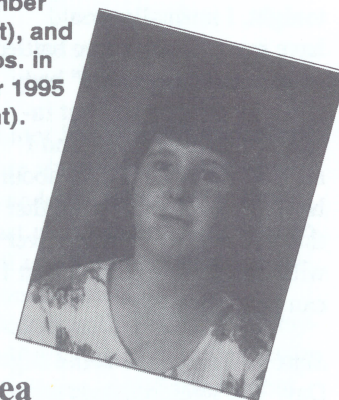
In addition to looking for a professional exchange, Donna would like to find a pen pal for Sidney.

Computer users can reach Donna at her e-mail address: [djones@YKnet.YK.CA](mailto:djones@YKnet.YK.CA)

Interested teachers who do not use e-mail can respond to Donna via the national office: PWSA (USA), 2510 S. Brentwood Blvd., Suite 220, St. Louis, MO 63144-2326.



Tamra at 124 lbs., November 1994 (left), and at 84 lbs. in October 1995 (right).



## Conquering Sleep Apnea

*Editor's note: Jim and Tammy Russell sent these photos of their daughter, Tamra, who was born in 1984 and diagnosed with PWS at age 4. By November 1994, Tamra weighed 124 pounds, was snoring and wheezing at night, taking naps, and wetting a lot while sleeping. A friend with a child with PWS told them these symptoms were common with apnea. That month Tamra entered a sleep study test, which showed she had central apnea. She was put on medication (Theolair, 300 mg), and her parents became convinced they had to get her weight down. They decided to put Tamra on a low-fat diet, which became an experience for the whole family, learning to read food labels, etc. Within a month she had lost six pounds and was much more active, taking fewer naps and learning more because she seemed more focused. Over the next year, the family's efforts really paid off. Jim and Tammy write:*

Tamra eats three (low-fat) meals a day and at 7:00 every night she has her snack, and she will remind you ... Food is the first thing on her mind in the morning and the last thing she mentions at night. We've learned, though, to let her know that this is the way it's going to be, to be firm and not give in, even though she's charming. We love her too much.

It has been almost one year, and Tamra has lost 40 pounds—we are so proud of her. She is off her medication and doing just great. So much more of Tamra has been brought out with this weight loss that it's exciting.

What we are trying to say is that apnea seems to be very common in children with PWS, that we as parents have to at least rule it out, and that it seems weight can be controlled. I say that lightly because we know how hard this is, but constancy pays off and so do locks.

We truly look forward to *The Gathered View*. It's so comforting to know we're not alone.

*Jim, Tammy, Scottie, and Tamra  
Prior, Oklahoma*



## Research

### Articles About PWS Published in 1995—Part 2

Last June, *The Gathered View* listed journal articles concerning Prader-Willi syndrome that had been published in the first half of 1995. Following are additional listings through December 1995.

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(Sources: MEDLINE, National Library of Medicine, and Uncover database, Colorado Alliance of Research Libraries. Note that listings with a single page number may be longer than one page.)

Editor's note: This listing does not include articles in languages other than English nor articles in *Prader-Willi Perspectives*, a quarterly journal devoted to PWS. For an index to *Prader-Willi Perspectives*, contact Visible Ink, Incorporated, at 1-800-358-0682.



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# The Trail to Eagle

by Angus MacDonald  
Redmond, Washington

*Angus MacDonald writes that he hopes this article about his son's travels up the trail to Eagle Scout will be an encouragement to other young people with Prader-Willi syndrome.*

Craig began scouting at the age of 6 as a Tiger Cub. With the help of wonderful leaders and his family, Craig moved up to Cub Scouts. Craig's mom served as an assistant den mother for his Cub Scout troop. Having Mom involved helped Craig with his decisions during meetings. Craig worked hard to accomplish his requirements and finally crossed the bridge to become a Boy Scout. His troop leaders were wonderful, taking him on campouts and trying to keep him away from the food. As time went on, Craig's dad had to attend all the campouts with him. It was not fair to ask the leaders to take on the extra burden of watching Craig without help from home.

It was not always easy for Craig, as many people did not understand the impact of PWS on endurance, strength, and social maturity. Craig's fellow scouts were mixed in their kindness and understanding. He experienced a lot of hurts to his ego, but his spirit was strong. Craig did his best to do his part in work projects and sell-a-thons. He loved feeling a part of the troop. He especially liked wearing his uniform. Craig's dad was in the Navy, and the scout uniform seemed to be a way he could be like Dad. He would always salute anyone else in a uniform when he had his on.

When Craig was 12, we moved back to Redmond, Washington. We called the local scout troop to discuss Craig's joining their troop. The troop leader, John Hardy, and his son came to our home to talk with Craig and us about his participation in their troop. We attempted to explain the effects of PWS. John was totally receptive. He didn't hesitate to assure us that the scouts and leaders of the troop would be there for Craig as long as Craig wanted to participate. None of us realized that evening just how far he would go.

Craig responded to his troop's support. He did not always fully understand all the activities and requirements, but he worked hard and listened hard in his own way. Again, the camping trips were limited to the ones his Dad could attend as the food temptations and need for supervision were not items to be passed off on other parents. Whenever possible, Craig was included, even if it meant he slowed down a leg of the relay race, lagged behind on hikes, took longer to set up his tent, or struggled with things that seemed to be easy for the other kids. The Senior Scouts were awesome in their defense of Craig. This helped the

younger ones to understand and tolerate the effects of PWS a little better.

When Craig achieved Life Scout, there were a lot of cheers. His pride in this accomplishment resulted in a new determination and vision that focused on Eagle Scout. His determination was often a bit more verbalized than actual progress would support, but he remained adamant that he "could do it."

There were setbacks. Impatience to sign off merit badges before all the requirements were checked off by the proper method resulted in a conference with his scout leaders. Several discussions were held on honesty. He didn't fully comprehend some of the consequences of his obsessive behavior or constant insistence that "his way" was right. There were times of doubt as to who was really going to benefit from his making Eagle Scout.

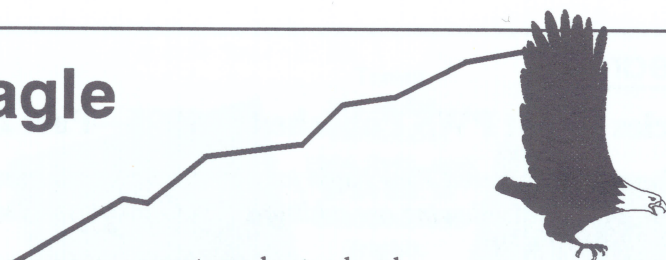
A big hurdle was the Eagle Scout Service Project. It was Craig's own idea to do a landscape beautification project for the PWS Group Home in Woodinville, Washington, and at the same time open up awareness for his fellow scouts as to what PWS is and what it's like to live in a group home. The impact was significant. Craig's efficiency was amazing as he went about getting plants, barrels, hoses, spare parts, fertilizer and bark. He was not shy about asking local merchants for donations to his project.

Craig's written report on his project, finishing remaining merit badge requirements, and filling out all the forms for Eagle Scout were accomplished with a generous amount of guidance from his scout leaders. Eagle Scout requirements must be finished by the 18th birthday. Craig went to the wire and finished two weeks before his 18th birthday. We had many doubts that he would make it, but he never did. He often tells us, "I told you I would make Eagle!"

One of Craig's visions was to announce his Eagle Scout achievement to the National PWS conference in July 1995. It was a very proud moment for Craig when he was able to stand up at the closing session of the conference and announce: "I have just completed all my requirements for Eagle Scout." He also acknowledged to the audience that he could not have done this without the help of the leaders.

Craig's Eagle Scout ceremony was held in November. He sent more than 100 invitations. He wanted to make sure that everyone he knew would be aware he made Eagle Scout. □

*Editor's note: Do you have a story of achievement to share? Please send it, with a photograph, if possible, to the Gathered View editors, c/o of the PWSA (USA) office.*





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