



# The *Gathered View*

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

## *Call for Photos*

by Barb Dorn

In the year 2000, PWSA (USA) will be celebrating its 25<sup>th</sup> anniversary. I am the chairperson for this celebration, which will feature a number of different acknowledgements over the entire year. One of the ways I would like to commemorate this event is through articles in *The Gathered View*. I also plan to create picture boards and possibly a video collage of pictures that will be shown at the national conference banquet in July.

I need help with the collection of pictures from past conferences and other events hosted by PWSA (USA) that will highlight events over the past 25 years. Do you have some great old photos to share with PWSA members? How about taking a little time to unearth them and, if necessary, make a copy for our big celebration? (I need pictures to be donated—they will not be returned.)

Please give as much information as you have about each photo—the date, the event, and the names of people pictured in the photo(s), if possible.

In order to use photos of individuals in the newsletter or any other publication, we will need written permission from the photo subjects. Any written permissions you can provide with the photos will be greatly appreciated.

Please forward all photos, descriptions, and permissions, along with your name, address, and phone number to:

**Barb Dorn**  
305 Amanda Way  
Verona, WI 53593

## 3rd Charity Golf Tourney Brings PWSA Funding ... *and a Brush with Celebrity*

Some of our chapters—and our individual member families—have been up to wonderful things on behalf of PWSA. A prime example is the spring O'Leary Golf Tournament, sponsored by O'Leary's restaurant in Missouri. Kevin O'Leary, who is family to PWSA members Judy and Tim O'Leary, co-owns the restaurant with his good friend, actor John Goodman. The tournament is held for the benefit of two causes: the Judevine Center for Autism and the PWSA Missouri Chapter. This year, the Missouri Chapter voted to donate \$1,200—40 percent of their receipts from the tournament—to PWSA (USA). Executive Director Janalee Heinemann attended the event to present a recognition plaque to Kevin, who organizes the event—and, of course, to rub shoulders with that lovable John Goodman ... who could resist?



**Above:** Judy O'Leary (left), Missouri Chapter President Mark Floretta, Kevin O'Leary, Janalee, and Tim O'Leary (Judy's husband).



**Left:** Actor John Goodman (far right), poses with Janalee, Mark Floretta, and golfer Tom Laritz.

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## The Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6  
Sarasota, Florida 34242

[www.pwsausa.org](http://www.pwsausa.org)

1-800-926-4797

9:00 a.m.—7:00 p.m. Eastern Time

Local: 941-312-0400

Fax: (941) 312-0142

E-mail: [pwsausa@aol.com](mailto:pwsausa@aol.com)

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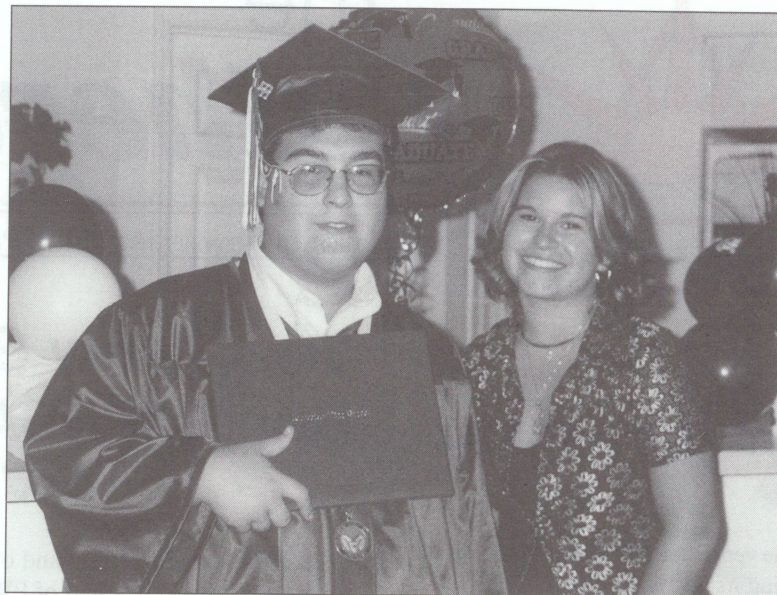
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## Meet Our Newest Staff Member

Many years ago, I wrote, "Although our children (siblings) will be partly damaged by the struggles that come hand-in-hand with PWS, they will also be greatly enriched." Our new part-time staff member, **Jessica Mancheno**, is the classic example of the "greatly enriched" component of this statement. Jessica's maturity, sense of responsibility, compassion, and understanding come from being in the trenches.

Jessica, who at 18 has just started college, is the only sibling of 21-year-old Michael. She hopes to be with us (school schedule permitting) for the next two years until she goes off to finish her degree and achieve her goal of becoming a nurse practitioner. She is pictured here with Michael at his graduation from high school in 1998.

Jessica is also an example of another statement I wrote: "It also warms my heart to see some of our siblings come full circle in becoming compassionate and responsible adults — not in spite of being a sibling dealing with PWS, but because of it."

—Janalee



### And the Winner Is ...

**Nanette Roenigk** of Reno, Nevada, won the drawing for PWSA logo merchandise—two T-shirts, a hat, and a CD holder—from among all who turned in conference evaluations.

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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.

Editor: Linda Keder ([keder@erols.com](mailto:keder@erols.com))

Associate Editor: Lota Mitchell ([ljecholsm@juno.com](mailto:ljecholsm@juno.com))

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, FL 34242. Telephone: 1-800-926-4797, or in the Sarasota area 941-312-0400. Fax: 941-312-0142. E-mail: [pwsausa@aol.com](mailto:pwsausa@aol.com). Web address: [www.pwsausa.org](http://www.pwsausa.org)



## Office Donations and Volunteers

### *Gifts-in-Kind*

We just received a wonderful donation from a local Sarasota physician, Maureen Maquire, of a nine-foot desk with built-in computer storage and side hutches. We also received a donation of file cabinets from Isreal Furmanský. The timing was great because we were at the point of feeling that no matter what else was going on, we had to get reorganized and go through files. Both staff and volunteers made that a major focus for the week and now feel much better about our headquarters.

Thank you, Maureen and Isreal!

### *Volunteer Appreciation Dinner*

The national office held a recognition party for its local volunteers at the home of volunteer Norma Rupe on August 13. The photo below, taken at the event, includes (from left to right) Ned Durell, Janalee Heinemann (executive director), Ann Coyne (bookkeeper), David Wayatt, Norma Rupe, Annie Durell, Al Heinemann, Bob Cumiskey, Carol Burnett, and Brenda Hagadorn (office manager).



## Chapters

The annual Chapter President's Day meeting was held on July 7, prior to the national PWSA conference in San Diego. PWSA President Barb Dorn chaired the all-day meeting, which was attended by representatives from 20 states or regions, as well as seven PWSA (USA) officials and board members. The group discussed relations between chapters and the national organization, chapter responsibilities, and proposals for fund-raising and awareness activities, then brainstormed chapter problems and solutions in small groups. They also heard a presentation by attorney Walter Lindstrom on obesity discrimination.

Those present voiced a desire to continue the annual national Awareness Week efforts, while providing flexibility to chapters to set their own timing for awareness events. Chapters were encouraged by the national PWSA representatives to conduct at least one awareness activity and one fund-raising activity each year. The national office will provide up to 400 free brochures a year for chapters to use in their education and awareness efforts. Chapters were asked to consider a proposal for an annual chapter agreement with the national association.

Active chapters and their current leaders appear at right. Additional contact information is available on our Web site: [www.pwsausa.org](http://www.pwsausa.org).

## PWSA (USA) Chapters

As of August 1999

### Regional Chapters

**New England** (MA, ME, NH, RI, VT) –  
Kim Silva, 508-238-7825

**Northwest** (WA, OR, ID, MT, AK, HI) –  
Billie McSwan, 206-285-2560

**Maryland, Virginia & DC** –  
Linda Keder, 301-384-4955

### Statewide Chapters & Affiliated Organizations

**Arkansas** – Jim Patton, 800-890-0887

**Arizona** – Teresa Kellerman, 520-296-9172

**Prader-Willi California Foundation** (affiliated) –  
Paul Paolini, 805-389-3484

**Colorado** – Lynette Hosler, 303-973-4780

**Connecticut** – Barb Farmer, 203-744-4189

**Delaware** – Karen Swanson, 302-836-6213

**Florida** – Dan & Judy Krauer, 561-334-7839

**Georgia** – Greg Talley, 770-518-4795

**Illinois** – Karen Engelhardt, 312-664-3090

**Indiana** – Jacque McGuire, 317-823-5748

**Iowa** – Tammy Davis, 319-686-4270

**Kentucky** – Willie Lacy, 502-968-2626

**Michigan** – Jim & Carolyn Loker, 616-353-7556

**Minnesota** – Neal Shapiro, 612-546-4926

**Missouri** – Mark Floretta, 314-839-0644

**New Jersey** – Doug Taylor, 973-628-6945

**Prader-Willi New York Association** –  
Mary Cucciaia, 516-328-6982

**Prader-Willi Alliance of New York** –  
Henry Singer, 716-442-1655

**Ohio** – Tom Guisti, 216-741-6778

**Oklahoma** – Daphne Mosley, 405-677-8089

**Pennsylvania** – Maria Silva, 412-369-4433

**South Carolina** – Rhett Eleazer, 803-345-1379

**Tennessee** – Terry Bolander, 615-790-6659

**Texas** – Diana Smiley, 512-989-2915

**Utah** – Pam Rauch, 801-277-9266

**Wisconsin** – Pat LaBella, 608-845-9597

*If your state is not listed, call PWSA (USA) at 1-800-926-4797 for more information or for local contacts.*

## *In Search Of ...*

● **Louisiana and Mississippi** parents, caregivers, or other interested parties to help form a regional chapter that will serve both states. Anyone interested in helping get this chapter off to a great start, please contact Velma Jones at 318-222-4689 or Gerri Merida at 504-834-4674.

● **Virginia** parents, service providers, and professionals to join our newly expanded regional chapter for Maryland, Virginia, and D.C. Call Stacey Diaz at 703-620-0330 or Linda Keder at 301-384-4955.



## **Bridging the Continents for a Better World for Prader-Willi Syndrome**

**Y**ears ago, when I was president of PWSA (USA) and USA's parent delegate for IPWSO (the International Prader-Willi Syndrome Organisation), I remember what a major ordeal it was to communicate with people from other nations. The time zones were often the most complicating factor, and cost was the other major issue. Today, with e-mail, these two complications have been taken away, and the invisible bridge e-mail creates is spanning the continents on a daily basis.

E-mail and better telephone and mail communication, as with television, have shown us the great needs and pain in the world that are hard to ignore. It has also shown us the strengths and the common bond we have with all families and professionals dealing with PWS. At the PWSA (USA) office and in the home of our current IPWSO delegate, Mildred Lacy from Kentucky, we struggle with how we fit into meeting the needs not only of our own "territory" (for Mildred of her Kentucky chapter, and for me the United States), but of a world awakening to the syndrome and its impact on the individual, the family, and the community.

The following are a few of the more poignant samples of contacts we have had at PWSA (USA) from other nations in the past year.

**Poland** — A summary of a mother's letter about her son: "The oldest 10 years old, has the PWS. His height is 153 cm, weight 300 lbs. He is [on a] moderate diet. He has had a heart attack." This woman contacted a mother in North Carolina through an interpreter, reporting that her son lost some weight, although his breathing problems continue.

**Africa/Ohio** — A social worker e-mailed about a newborn: "The family is from Africa and does not speak English. I am petitioning the Court for the State of

Ohio to become the child's custodian. ... Sadly, they consider developmentally handicapped babies [to be] born without souls in Africa; they are left to die. Are there any pediatricians in central Ohio who specialize in PWS? Anyone speak English/Tigrania language?"

**Mexico** — A sister e-mailed: "My brother was born 28 years ago in Syracuse, N.Y. His major issue has been obsessive-compulsive disorder. He gets violent and can certainly hit and start a terrible tantrum and screaming. Then we all suffer, and the worst part is that peo-

continue in his school. Now he spends all his time in the house, can't go out, refuses to see or deal with anybody except me and his father."

**Canada** — A call from a physician regarding a child in respiratory failure: He weighs 350 lbs. and has been on oxygen for two weeks. Questioned if a tracheotomy was an option with a PWS patient. Asked to talk with a physician specialist to set up guidelines.

**Of course, there are also the connections that put a smile on our face such as:**

**Japan** — A congressman from Japan (friend of the Shackletts in Oklahoma) ordered 100 PWS aprons for the women to wear at their campaign dinner, and the daughter e-mailed: "My parents received aprons and brochures as well!!!!!! They are extremely excited to use them now!"

**El Salvador** — An e-mail from El Salvador states: "The present is to sincerely thank you, for today I was very happy to receive the package of information you sent us. I haven't been able to go through it all yet, but I couldn't wait to thank you, for this represents so much to us. It's nighttime here in El Salvador, but early tomorrow I'll make sure that Jesus J. mother gets it. Thank you again, and I will most surely bother you as I read the whole set of information. Our best wishes for you and your dear."

**Japan** — A mother e-mails: "Thank you so much for your kind e-mail of 17 Sept. We sent our photo to you. If you favor them, we are happy. ... [Our son with the syndrome] grew corns and egg plants and cucumbers from seed in front of our house in this summer. It was the first time for him. He has studied planting in his special education need class. We eat corns. It tasted sweet. I can't grow plants from seed. He is a good little farmer."



ple don't cooperate and sometimes they send the cops and so on. So we're at a point in which we don't know what to do. I think that he shouldn't go to stores, but my Mom thinks that it will be a terrible fate to lock him in the house. Unfortunately, here in Mexico there are no programs for mentally retarded adults. Right now my mother is terribly depressed, and she cries all day long because she doesn't know what to do and she knows she isn't getting any younger. But right now we're all like facing a dead end street without knowing the next step."

**Egypt** — A letter from a mother: "I am an Egyptian mother. I have a child with PWS. I wish to attend this conference (the international) because here in Egypt, there is not much information or knowledge about PWS. It took me six years to know the real cause of my child's abnormal behavior. ... About the child himself, he became so nervous and very aggressive because of his disability, he couldn't



**England** — Our favorite “pen pal” is a young man from England, who has written us at least 30 times in the last six months! We have our volunteer, Siobhan, and a young staff person, Jessica, correspond with him. In one recent letter he wrote, “I would like a perminate (*sic*) girlfriend age 18/19 or over from Alaska, Colorado, Liverpool, or from Boston, or Chicago with PWS. I like discos, line dancing, computers, 10 pin bowling, the gym, going to the movies. I also like having a circle of friends with PWS, but I dislike loneliness, boredom, and getting teased about my color and weight.”

In a few weeks, Mildred and I will be meeting with the president of IPWSO, Giorgio Fornasier of Italy, and Joan and Jim Gardner of Minnesota, who will be our hosts. We are grateful to the Gardners for providing us with the opportunity to do some true sharing. Our two major topics will be: 1) How we can provide better communication and support to all nations? 2) How can we work together to make the 2001 IPWSO/PWSA (USA) conference in Minnesota an outstanding conference? (Thanks to the Gardners and the Minnesota chapter, it is well on its way!)

I would like to close with a quote from a recent e-mail from Giorgio that humbled me and had an impact that I hope stays with me while we explore these exciting opportunities and challenging responsibilities to our world of PWS:

“IPWSO does not belong to anybody particularly but to everybody. We cannot impose any stereotype or model to be followed blindly, we cannot create or propose any predominant culture, behavior or diet to be followed and we shouldn’t criticize who are different or not able to do what ‘official representatives’ are used to do ‘by nature’ or ‘by luck.’ We must respect all cultures and experiences, as we have to learn from everybody: PWS esquimo families in Greenland as well as PWS families in Namibia or Paraguay. In my opinion we have never to talk about 1st, 2nd and 3rd World in an International Charity Organisation like ours, but must talk about rich and poor countries, as money makes the difference anyway, and money is important to be organised and successful, as clearly mentioned above. Rich countries must help the poor ones offering means and opportunities, not trying to colonize them either as parents associations or professional contacts among scientists and doctors. English language is a ‘means’ — we do need to understand each other — but cannot be a ‘must.’

“Technology and scientific level are also ‘means’ not things to show we’re different, inferior or superior. E-mail is a fantastic way to communicate and assist people and Internet a window in the world which any desperate family can open and realize the sun is shining.”

(Giorgio Fornasier, IPWSO president)

## IPWSO’s Logo

The official logo of the International Prader-Willi Syndrome Organisation (IPWSO), shown below, was the winning entry submitted in a logo contest held in 1997-98. It was unveiled at the Third International PWS conference in Italy in May 1998.

The logo’s creator is Tiina Silvast, a graphic designer and the mother of a teenage daughter with PWS. Tiina is the parent delegate to IPWSO from Finland, and she has chaired the Finnish PWS association for a number of years.

Of her winning design, Tiina says,

“When I started to design my proposal of IPWSO logo, I wanted to forget vegetables, fruit and other kind of healthy food, which so often are present when talking about Prader-Willi syndrome. I ended up with a golden heart, a symbol of goodness and caring. The heart began to look more and more like an apple and then like two carrots. And there it was again, a logo with healthy food. But most of all, with a heart. I wasn’t sure if it repre-

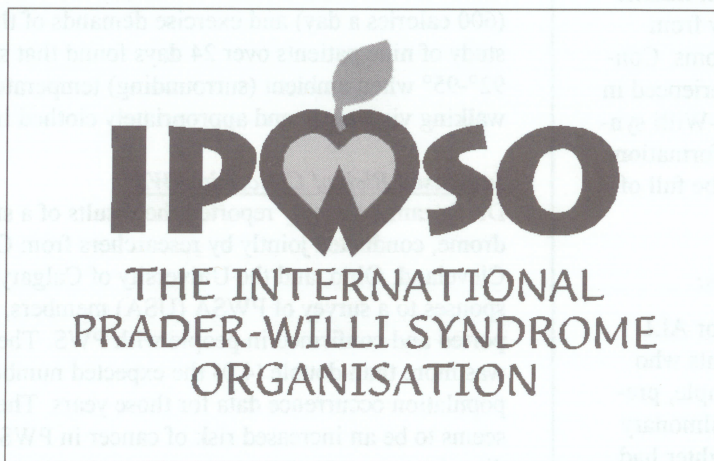
sented more the people with PWS than IPWSO. And for that reason it got a leaf to tell about possibilities. ... my main goal was to make something that is warm and friendly. It must tell at the first sight that it represents an organization which works for human purposes.” (*Wavelength*, Vol. 7, Issue 1, 1998)

In full color, the logo has black lettering, with orange in the center of the heart and a green leaf sprouting from the top.

## New IPWSO Web Site

IPWSO has developed a new Web site—and it’s soon to be hosted by PWSA (USA)! You can link to it now and after its move through PWSA’s site: [www.pwsausa.org](http://www.pwsausa.org).

There you will find the complete list of IPWSO member countries, as well as contact information for the parent and professional delegates from each country.





# On Respiratory Virus in Infants

*PWSA received the following comment by e-mail from a registered nurse:*

"None of the material I've viewed on your Web site addresses how serious a respiratory infection can be for an infant with Prader-Willi due to their hypotonia and weak cough. A particularly dangerous virus, RSV (Respiratory Syncytial Virus), can now be prevented by a vaccine. It should be suggested that infants with Prader-Willi be kept away from anyone with respiratory symptoms. Consultation with a physician experienced in the care of infants with Prader-Willi syndrome will afford you more information. Otherwise I found your site to be full of very good information ..."

**Dan Driscoll, M.D., comments:**

RSV is a dangerous virus for ALL infants, particularly those infants who are more vulnerable—for example, premature babies with broncho-pulmonary dysplasia (BPD). My own daughter had RSV as an infant and now has reactive airway disease (asthma).

I personally follow over 70 patients with PWS and none has had a severe case of RSV to my knowledge, but I agree they would be more vulnerable due to the hypotonia.

According to my expert colleagues, there is no vaccine for RSV that they are aware of at the present time. There is however "Synagis," which is an IM immunoglobulin injection given monthly during "RSV" season and which costs over \$900 a shot. This is reserved for the most vulnerable infants (e.g., those with BPD), and I would not recommend it as standard prophylaxis for PWS unless the infant had been a premature baby with BPD.

*(Dr. Driscoll is a PWSA board member and co-chair of the association's new Clinical Advisory Board, which is currently being formed to address treatment questions.)*



# 1999 Medical Reports

Several interesting medical reports were presented at the PWSA Scientific Conference in San Diego in July. Following are brief summaries of these reports. The complete abstracts for all of the Scientific Day presentations are now available on PWSA's Web site: [www.pwsausa.org](http://www.pwsausa.org).

### Hypothermia in Some With PWS

Drs. James and Jeanne Hanchett reported on two patients seen at The Children's Institute in Pittsburgh who had recurring hypothermia syndrome—abnormally low body temperatures of 81°-94° F. The patients, both in their forties, first developed hypothermia in late November living in the Mid-Atlantic region and had recurrences in subsequent winters. The hypothermia and related physical changes (including decreased blood pressure and slow respirations) returned to normal when the individuals were rewarmed and were not made worse by the strict diet (600 calories a day) and exercise demands of the PWS Program at TCI. A further study of nine patients over 24 days found that six "dropped their temperature to 92°-95° when ambient (surrounding) temperatures were below 66° F, despite walking vigorously and appropriately clothed in an exercise program."

### Increased Risk of Cancer in PWS

Dr. Suzanne Cassidy reported the results of a study of cancer in Prader-Willi syndrome, conducted jointly by researchers from Case Western Reserve University in Cleveland, Ohio, and the University of Calgary in Calgary, Alberta. Of 1,077 responses to a survey of PWSA (USA) members, 32 instances of tumors were reported and confirmed in people with PWS. The occurrence of cases in 1990-94 was more than double (4.0) the expected number (1.26), based on general U.S. population occurrence data for those years. The researchers concluded that there seems to be an increased risk of cancer in PWS, as there is in a number of other disorders.

### Decreased Bone Mineral Density Due to Lack of Bone Development?

Dr. Merlin Butler of The Children's Mercy Hospital in Kansas, and colleagues at Ohio State University in Columbus and Vanderbilt University in Nashville, Tenn., examined 25 adults with PWS and compared them with 14 obese, non-PWS adults regarding their bone mineral density (BMD). Although the subjects with PWS had significantly lower total bone mineral density than the obese subjects, their urine studies did not indicate a higher rate of bone loss or resorption than the control group. The research suggests that low BMD and the high occurrence of osteoporosis commonly found in PWS is due to insufficient bone-building during development rather than to bone loss or active degradation of normally developed bone.

### Early Onset of Type II Diabetes in PWS

Dr. Susan Sell and colleagues from Birmingham, Ala., and Vanderbilt University in Nashville, Tenn., report that Type II diabetes—the kind associated with obesity—occurs at an unusually young age in individuals with PWS. In a study of 34 individuals with PWS taking part in the comprehensive PWS research at Vanderbilt, it was found that 10 were diagnosed with diabetes, seven of them before age 14 and the remaining three by age 20. The researchers conclude that this early age of onset "may reflect underlying diabetes susceptibility brought on by severe obesity at an early age and the relative reduction in muscle mass." (It should be noted that none of the participants in the Vanderbilt study are on growth hormone therapy.)

—Linda Keder



## Research

### The Use of Psychotropic Medication in Persons with Prader-Willi Syndrome

by Drs. Judith A. Brice and Jeanne Hanchett,  
The Children's Institute, Pittsburgh, PA

*(Following is the authors' 1999 PWSA Scientific Conference abstract, edited for length.)*

Behavior problems associated with Prader-Willi syndrome are legendary to those caregivers who work with patients with the syndrome. ... Most of the diagnoses of our patients elude a helpful DSM-IV description. *(Editor's note: The DSM-IV is a manual of psychiatric diagnoses)* "Personality Change Due to a Medical Condition," "Atypical Psychosis," or a description of behaviors in the "Not Otherwise Specified" category are the most faithful to the DSM-IV nomenclature, although these diagnoses are far from helpful in clarifying treatment or course of the symptoms.

In our experience at the Children's Institute, we have found that the combination of a very structured, comprehensive behavioral program, including group therapy together with the judicious use of psychotropic medications, can be very helpful in curbing many of these very disturbing behaviors and mental processes.

The use of psychotropic medications in 65 patients admitted consecutively to The Children's Institute in the year 1998 with the diagnosis of Prader-Willi syndrome is reviewed as exemplary of the drugs chosen and used in our work with these patients at The Children's Institute. Included among the medications prescribed are Prozac, Zoloft, Paxil, Buspar, Ritalin, Clonidine, Klonopin, Desyrel, Depakote, Zyprexa, and Risperdal.

... It has seemed most prudent to target certain symptoms (rather than a specific diagnosis). It also is advisable to try a single medication at a time and push it to its maximum recommended dose or to the dose where disturbing side effects emerge. At this point a second medication is then introduced. This process obviates making two changes in medications at the same time, a situation which is often fraught with difficulties, especially if side effects occur.

*(Editor's note: Additional reports on behavior research will appear in a future issue of The Gathered View.)*



Dr. Jeanne Hanchett, left, was recognized at the 1999 national conference banquet for her many contributions to PWSA. Dr. Hanchett serves on the Scientific Advisory Board, was co-author of the association's Health Care Guidelines for Individuals with PWS, and has shared much data and research from her years as medical director for the PWS Program at the Children's Institute (formerly The Rehabilitation Institute of Pittsburgh). The award was presented by PWSA Board Chair Ken Smith and Executive Director Janalee Heinemann.

### *In Search Of ...*

#### **PWS + Mitochondrial Disease**

Several cases have come to light of children who have a dual diagnosis of Prader-Willi syndrome and mitochondrial disease. The term "mitochondrial disease" describes a number of degenerative diseases caused by genetic defects in a tiny portion of the body's cells called mitochondria. Mitochondria vary in their shape and function, depending on their location in the body, and cause a complex array of symptoms when they malfunction.

The national PWSA office would like to hear from any other families who have received this dual diagnosis on their child with PWS. (1-800-926-4797)

#### **Wheezing Problems Resolved after GH Treatment**

Dr. Robert Wharton, co-chair of PWSA's new Clinical Advisory Board, has recently seen a 3-year-old girl with PWS who had considerable wheezing problems. Four months after starting growth hormone therapy, the parents reported to Dr. Wharton that the child's wheezing had stopped.

Dr. Wharton would like to know of any other children with PWS who had a wheezing problem that stopped after beginning GH treatment. Dr. Wharton can be reached at 617-573-2637.

### **First Announcement**

#### **The 15th Annual Scientific Conference of the Prader-Willi Syndrome Association (USA)**

will be held

**Wednesday, July 19, 2000**

Followed by PWSA's 22nd National Conference, July 20-22  
Pittsburgh, Pennsylvania

The 2000 PWSA Scientific Conference will include papers on genetics, medical problems, growth, and behavior.

If you are interested in presenting a paper and want further information, contact Dr. Jeanne Hanchett, Scientific Conference Chair, at: 1-412-420-2328, or by fax: 412-681-1061.



"The conference was excellent. I am amazed at the professionals out there helping our children with PWS. All are very concerned and took the time to explain their field in detail to all of us. Even getting one-on-one questions answered was easy. ... To old friends and new friends, I am proud to be associated with each and every one of you (as a PWS family). It always feels that way, like an extended family."

—Julie Klaus, Livermore, California

# San Diego Dreamin'...

## Kudos to California!

PWSA congratulates and thanks the Prader-Willi California Foundation—especially our Conference Co-Chairs Frank and Fran Moss, and Youth Program Director Linda Ryan and her husband, Mark—for another stellar PWSA national conference. A few photo highlights:



*Above:* Master-of-Ceremonies Mark Ryan (right) introduces Fran and Frank Moss to the banquet audience before starting the "Prader-Willi Quiz Show." *Right:* Four contestants were plucked from the audience to answer questions; Kentucky Chapter President Willie Lacy (far right) was the winner!

*Top left photo:* Lota Mitchell (left), 2000 Conference co-chair (Pa.), poses with Bronnie Maurer (S.C.) and D.J. Miller (Pa.), whose families were recognized as the only ones to have attended all 21 PWSA national conferences.

*Left:* Drs. Louise Greenswag and Barb Whitman, PWSA Director and Scientific Advisory Board member.

*Bottom left:* New Director Carolyn Loker and Clinical Advisory Board Member Dr. Jim Loker (also Michigan chapter presidents).

*Right:* PWSA Director and Clinical Advisory Board Co-Chair Dr. Dan Driscoll, Past President Jerry Park, and Treasurer Jim Kane.



*Near right:* PWSA Vice President Mary Lynn Larson (Wis.), Debbie Fabbio (Pa.), and Iowa Chapter President Tammy Davis.

*Far right:* The now traditional "passing of the conference torch" from Fran Moss to Pennsylvania Chapter President Maria Silva, 2000 Conference co-chair.





# 1999 Conference Memories

## Youth & Adult Program

by Linda Ryan

During the July 1999 PWSA conference, over 300 of our children and adults participated in a fun-filled Youth/Adult Activity Program. As this year's YAAP chairperson, I had the opportunity to work with John and Debbie Stallings of Josh's Friends and their professional staff of assistant directors, Katie, Sarah, Kim, and Janette. They are at the beginning of a long list of people whom I must thank for making possible this year's youth conference—our largest ever.

Kudos to the teachers—Ida Shah, Gloria Stanton, and MeMe Jacobs—for entertaining the toddlers with crafts, stories, and games while the older group spent time in the Garden Pavilion atop the fourth floor of the Westin Hotel. Thursday featured a lively mix of storytellers, zoo animals, a magician, and a carnival. Despite the heat and some sound difficulties, the performers continued to give their all throughout the day. All of the participants were thrilled with the assortment of prizes and a dozen video games on free play. Many thanks to family and friends who manned the carnival booths for the entire day.

Friday's field trip to the Birch Aquarium, Balboa Park, and Omnimax Theater would not have been possible without the outpouring of volunteer support that came from within our own organization. Thank you to all of you who gave up your time at the adult conference, college, or work to make it possible for the youth to have a safe, fun day in San Diego. Michael Alterman deserves a special mention for all of his help throughout this and past conferences. (This year we owe him a new shirt for his efforts in keeping everyone calm and together!)

At our Friday evening banquet, tables beautifully decorated with sailor hats and ship's wheels generously provided by Roda Guenther and family provided the backdrop that helped everyone "set sail" into an exciting evening. "You Should Be Dancing" entertained with great music, electrifying lighting and energizing DJs. Thanks to all of you as well.

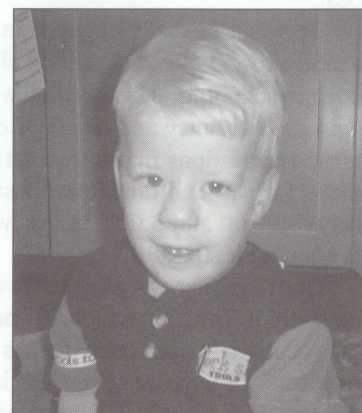
The BINGO on Saturday included more great prizes and an address exchange to help make saying goodbye a little easier.

Words of thanks go out to everyone who worked so hard and volunteered their time. Fran and Frank Moss, Michele Freier, Bud and Bev Bush, Maureen and Paul Paolini, Mark Ryan, Mike and Marilyn Ryan—thank you all very much for all of the time and energy devoted to making YAAP a success! This year's YAAP went a long way in promoting friendship and awareness of the special needs of our youth and adults with Prader-Willi syndrome. It was a wonderful experience for me to see the power of many individuals gathered together for a common goal—the happiness of our children.



**"[My son] had never met anyone with PWS and that was really the goal in our coming. Dallyn now knows that there are other special children like him, and that means a lot. We were really impressed with the whole organization of the YAAP program and the attention to the needs of each participant as an individual."**

*—Kim Nicholas, Calgary, Alberta*





## Back to School ... One Day at a Time

I hope all parents of school-age children are starting off their new year on a good note. Oftentimes, it takes a bit of time to get all of the "bugs" worked out. We are off to an exciting start to a new school year in our household. Tony, my son who has PWS, is now in eighth grade and his brother, Tyler, is in seventh. The middle school years ... a time we all try to grin and bear.

Tony isn't exactly engaged in the academic challenges of school. He has been in school for 12 days now with one episode of truancy and two days of intense negotiations in order to get him there. Life around the Dorn household between 7:00 and 8:00 a.m. on weekdays is often a bit stressful.

One area that is starting off very successfully is Tony's new job. As part of his vocational experience, he has started working at a daycare center. He is working two days a week, 1¼ hours each day. He is so excited and so proud. Today he came home in jubilation over reading a story to the kids and helping a boy "pull up his pants." He told me, "I think I am going to be a very good uncle some day." He also said he thinks he is going to do this job "forever." It warms my heart to see him find a job that he enjoys so much.

Tony has always liked being around younger children. Most of his "play-mates" in the neighborhood are younger kids. This summer you would have thought he was the Pied Piper. He had younger children following him around. He would read to them, play imaginary games with them, as well as include them in other activities. We all have our fingers crossed that this will continue to be a successful experience for him.

You may be wondering, "How do they handle the food at a day care center?" Tony eats his snack with the other kids. By the time he arrives, there is no longer an issue with a meal and he leaves before lunch is served. I think that Tony will do just fine at meal times as long as his responsibilities are outlined

and structured. He will need to know when and what he will eat. He will need a job or responsibility that isn't asking him to take on too much "control" over his eating. It may be that Tony has his lunch break at the same time as the kids but in a separate area. Structure and supervision will be the key.

Last year, Tony worked one afternoon in our local library. He started the year before by working in the school library. Tony has always loved books, and this environment was a safe, successful one for him. He did, however, want to do something with kids. The daycare posi-

tion will be another opportunity for him to gain some successful work experience.

I often wonder, when Tony is an adult, where will he live? Who will he live with? What kind of job will he have? And most important ... will he be happy? I have learned to take things one day at a time. I am hopeful that his future will be a positive, productive time for him. I guess we want these things for all of our children. Many of our children, however, make us work a bit harder at getting there.

Take Care.

### Book Review

## ***The Explosive Child***

by Ross W. Greene, Ph.D. (HarperCollins, 1998)

*Reviewed by Marty Girdaukas, RPh., parent of a child with PWS, Madison, Wis.*

**Attention! Attention! Attention!** There is a new book out that may be of interest to all of you. It's called *The Explosive Child*, by Ross W. Greene, Ph.D. Much of it could be pages written from my life. My friend said that she was wondering if Dr. Greene was peeking at her family through the window.

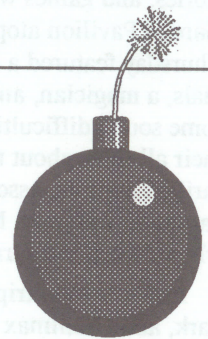
Now all of us have heard about the diagnoses, the lists of symptoms, the characteristics, and the problems that we face on a daily basis—but what good is that? This book is about solutions! It is a step-by-step guide to help you and your child build the skills necessary to avoid behavioral explosions. This book goes into specific details to explain what is happening to the child when that child loses control, how to recognize the changes occurring, and describes exactly when and how to intervene to prevent "explosions."

Dr. Greene explains why many traditional disciplinary and motivational strategies do not work well with these children. Then he gives several tools and strategies for parents, children, teachers, child-care providers, and others that are proven effective in building flexibility and self-control. This book can also be very useful for explaining to school officials (who have difficulty understanding or believing parents) how best to handle certain problems occurring in school. It is available from major booksellers and is worth its weight in gold. Happy Reading!



*Editor's note: The Explosive Child lists at \$24. Amazon.com, an on-line bookseller, offers the hardback for \$16.80, an abridged audiotope version for \$14.40, and advance orders on a paperback version (due out in February) for \$10.40, plus shipping and handling.*

Dr. Greene is a child psychologist and researcher at Massachusetts General Hospital and Harvard Medical School. He has a Web site ([www.explosivechild.com](http://www.explosivechild.com)) that gives more information about his book and lists upcoming workshops on "Understanding and Helping Inflexible, Easily Frustrated, Explosive Children."





# What A Great 'IDEA'!

by Jacquie Brennan

Brennan & Associates – Attorneys At Law, Houston, Texas

**W**hen parents have a child with a disability, they begin to learn a whole new alphabet soup of abbreviations and acronyms. For parents of children with Prader-Willi syndrome, the first is PWS, but it's not the last. Once a child starts to school, parents begin to hear about IDEA, IEP, LRE, FAPE, and a whole host of sometimes confusing letter combinations. Over the next few issues of *The Gathered View*, we will focus on different parts of the Individuals with Disabilities Education Act (IDEA).

The underlying principles of the IDEA are that:

- Education is to be provided to ALL eligible children with disabilities;
- Education is to be provided in the least restrictive environment;
- Education is to be provided at no cost;
- Education is to be individualized for each student with a disability; and
- Compliance with IDEA is ensured by means of procedural safeguards.

IDEA covers children with disabilities from the age of 3 years, although some state agencies provide programming for children from birth. IDEA mandates coverage through the 18th birthday, although again, many states offer services through the school year in which the child turns 21.

FAPE stands for "free appropriate public education," and IDEA says that all children with disabilities are entitled to a FAPE. This is a somewhat vague mandate. The most frequently litigated word in all of IDEA is "appropriate." What constitutes "appropriate" is subjective, and there is frequent disagreement between parents and school districts about whether an educational plan is appropriate. While it may be difficult to determine what appropriate truly means, we know that one thing it does not mean is "the best." Schools do not have to provide the best possible educational pro-

gram for a child with a disability. They must provide a program that is appropriate.

LRE stands for "least restrictive environment." This means that children with disabilities are to be educated with children without disabilities to the maximum extent appropriate (there's that word again). Although the placement of all children with disabilities in the regular classroom is the goal of IDEA, Congress recognized that this placement would be inappropriate in some circumstances.

**"... The most important letter in IEP is the I."**

This is reflected in the regulation which requires school districts to develop a "continuum of alternative placements." Most states have a "cascade system," which starts with the regular education classroom as the ultimate goal and then lists a number of increasingly more restrictive placements, with the policy that students should be moved into the more restrictive placements only as necessary and should be returned to less restrictive placements as soon as possible. A school must give written reasons in the IEP why a particular placement is the LRE that is appropriate for that student.

IEP stands for "individualized educational program." This is the heart of IDEA and will be the subject of a more detailed analysis in a future issue of *The Gathered View*. An IEP must include, at least, the following:

- The present level of education performance, including how the child's disability affects involvement and progress in the general curriculum;
- Special education and related services and aids, modifications, and supports provided to advance toward attaining annual goals, and to be involved and

progress in the general curriculum and extracurricular activities;

- An explanation of the extent to which a child will not participate in the regular classroom;
- Modifications needed for the student to participate in standardized assessments;
- Frequency and location of services and modifications;
- Beginning at age 14, transition service needs which focus on course of study;
- Beginning at age 16 or earlier, a statement of transition services and inter-agency responsibilities; and
- How the child's progress toward annual goals will be measured and how parents will be informed of the progress.

It is extremely important to remember that the most important letter in IEP is the I. The program must be individualized to each student's special needs. For a child with PWS, an IEP should address food issues in detail, as well as behavior issues.

In the next issue of *The Gathered View*, we will look at the issue of discipline. I have heard from parents of children with PWS whose children have been unlawfully expelled from school for behaviors that are manifestations of the syndrome. This is a difficult issue, because IDEA regulations have only recently been issued to cover the 1997 amendments relating to behavior and discipline. School districts are making mistakes, and children with disabilities are sometimes being denied an appropriate education.

If you have specific legal topics you would like to see addressed in this column, please contact:

Jacquie Brennan  
2402 Commonwealth  
Houston, Texas 77006  
713-522-1211  
Brennan@LawBrennan.com.



# Homework ... A Lesson in Frustration

by Barb Dorn, Parent, PWSA (USA) President, and Executive Director, PWSA of Wisconsin

*Over the past eight years, I have learned to hate the concept of homework for my son who has PWS. He is now entering eighth grade. It has only been within the past two years that I have been successful in stopping this practice. It was either stop it or allow it to destroy our family time. The following editorial article is my family's view on this common educational practice. As my son grew older, the challenges of homework grew more intense. There may be students who have PWS and families who do not face this challenge. But for those of us who do ... this article is for you.*

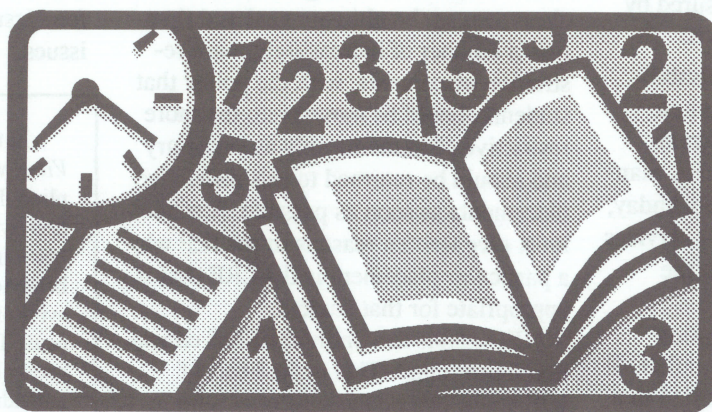
Homework is a concept or task that all of us experienced as a child. A teacher taught us the material; we performed in-class exercises; and then we practiced what we learned in out-of-class work. Homework can teach many students responsibility and accountability. It can help the student transfer the learning process from school into the home environment. For many students with PWS, however, transferring or generalizing what is taught in school to the home is the difficult part. Homework can create at-home chaos and emotional upheaval for the family.

Transferring learning from one environment to another is a common challenge that many students who have cognitive or learning differences experience. What that means is that a child may seem to have a clear understanding of a concept or task at school, but when he or she is asked to perform that task outside of the area in which they learned it, they are often unable to do so. Add to that the fact that many of the methods by which we were taught are not the same methods used to teach our children today. So when well-meaning parents try to reinforce or re-teach a concept during homework time, the child with PWS becomes confused and anxious because the parent is explaining things in a new or different way. Battle can then begin when the student with PWS wants to complete the

assignment but the parent lacks the expertise to teach the material in a consistent manner.

Many students with PWS often do not see parents as teachers (even though that can be one of our undercover primary responsibilities). As parents we are very aware that many children and adults with this disability rely on the "expert" or "boss" in a situation for the final decision. Parents are not often viewed as the math (or reading or science ...) expert.

We know that many people who have PWS are visual learners. We also know that they have poor auditory short-term



memory. If exact instructions or assignments are not clearly written down, the student often can't remember what or how to complete the work. The parent is often placed in a "no win" situation — the parent's word against the child's word. As emotions escalate, logic and learning are lost. The end result is an evening of frustration and tears.

Many students with PWS work very hard all day long to stay focused and in control. They are faced with many challenges academically, behaviorally, and socially. They view home as a place to unwind, relax, and work on home-related activities. When the task of homework faces many of these children, they can quickly escalate to tears, tantrums, or both. I have called teachers at home during these times to let them briefly hear and experience all that can go into a "simple misunderstanding."

Siblings often try to help out as well. This is especially true when the sibling is older than the child with PWS. However, the younger sibling quickly surpasses the older child in the area of academics. At times this situation can be very successful. There are other times when the whole household gets pulled into the emotions that accompany misunderstanding.

I have heard parents remark that if their child did not do homework they would be "giving up on" him or her. I strongly believe that we

are not giving up on our children when we ask for sanity and peace in our homes. Homework often interferes with our ability to keep our family life under less stress. We face so many challenges; out-of-school work should not be one of them.

Parents become experts at interjecting learning so that the child is unaware of



what we are doing. This is a strategy not unique to parenting a child who has PWS. We often use this on all of our children. We “sneak in” ways for our child to use math skills: “We have four people eating supper tonight, and they each get two dinner rolls. How many dinner rolls should we cook?” We also utilize the news or favorite TV show to point out geographic locations. Mind you, we must be very clever and sneaky in doing this teaching.

I do feel that home should be the place where we teach home-related responsibilities and expand upon social opportunities. We should be teaching and reinforcing grooming and household tasks. As the “parent-teacher,” we are responsible for teaching bathing and other hygiene tasks. We also instruct on bed making, laundry, and cleaning responsibilities. Finding appropriate recreational opportunities is also a job we undertake.

I have always been willing to assist in “homework” such as a trip to the library to obtain a good book for recreational reading. I have also been willing to provide a structured time with my son and a few friends so that he can expand his social skills. Inviting friends for a visit can teach many valuable lessons — phone skills, speech and language skills, sharing, as well as many other life skills.

When we look at our own work commitments, we all become a bit cranky when we start to do too much “work” during our family time. Most children with PWS have some degree of cognitive (learning) and/or behavior limitations. They need to have expectations in the area of homework modified — eliminated. As the child and family advocate, we need to communicate the need for home time to be a time of positive social and leisure opportunities. Educators need to support the separation of school-work and homework. We are not giving up; we are focusing on different yet very important areas of our child’s learning.



## ‘Recycled Love’ Program

**T**he Minnesota mother of a 14-year-old son who weighs 340 pounds and is just going through testing for PWS called to ask for help and a crisis information packet. During our conversation, she told of their desperate need for adequate clothing and of how her son cries because the kids at school make fun of him — partially because he has only two shirts and one pair of pants that fit. He also needs shoes that fit and a winter coat. The 10-year-old boy from Poland, who weighs 300 pounds, and about whom I write in my Executive Director’s column (p. 4), also desperately needs clothing. We have received calls from other parents as well who are in the same situation.

Although the greater need is weight loss, we cannot ignore the immediate need for shoes and clothing. We can refer families to manufacturers of large-size clothing, but many cannot afford the cost of it. Meanwhile, we have families who are fortunate enough to have seen dramatic weight loss in their child (often after placement in a residential program), so “somewhere out there” is a pool of used clothing in very large sizes that would help other families immensely. To connect the families in need with those who have unneeded clothing, I would like to set up a volunteer program through which we recycle clothing in the very large sizes. We’re calling it “*Recycled Love*.”

While our larger goal is to get to the point that no child has to deal with the medical and emotional trauma of excess weight, we can relieve some suffering now if we pool our resources to help those in desperate need.

To launch *Recycled Love*, we need :

**1. A volunteer to take calls, maintain lists of available clothing, and arrange the transfers.**

PWSA would give the families who wish to donate clothing the number of the volunteer coordinator. The family would be asked to keep the clothing until we have a family in need. The volunteer program coordinator would connect the two families, or tell the donor where to mail the clothing if the family doesn’t want their name to be given out. The volunteer’s related phone costs could be reimbursed by PWSA (USA).

**2. The names of families with clothing to donate—including descriptions and sizes of items.**

**3. The names of families in need of large-size clothing—including specifics and sizes.**

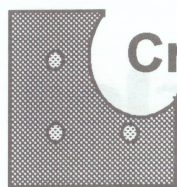
Once we have a volunteer, we will post that individual’s name and number in each issue of *The Gathered View* (under the heading *Recycled Love*) and on the PWSA Web site.

If you’re willing to volunteer for the job, please contact PWSA right away. Until then, you are encouraged to contact our national office if you have either extra-large clothing to donate or a need for such clothing.

Many years ago, I wrote, “*Being a Prader-Willi parent is being elated when your child gets down to a size Husky!*” That was when our son, Matt, was 8 years old. By the time he was 9, he was an average size — and has remained that way for 17 years. Our ultimate goal is the same for all families.

—Janalee





## Crunchin'

by Bev Ekaitis, DTR,  
The Children's  
Institute, Pittsburgh

Crackers can be a great choice for a low-fat, tasty snack. They make an appetizing alternative to potato chips and buttered popcorn, which can be loaded with fat and calories. Choose low-fat crackers such as melba toast, crispbreads, and matzos to add a healthful crunch to your snacks.

There is a huge selection of types of crackers available in the supermarkets today. Not all of them are good choices. Some crackers can be very high in fat and sodium. It is very important to read the label to find crackers that have less than 4 grams of fat per serving. Watch for added lard and animal fats, palm, palm kernel, or coconut oils in the list of ingredients. These are the types of fat that are especially important to avoid because they are saturated.

Even if a cracker box states "unsalted," there is still a good chance that a large amount of sodium is baked into the crackers—they may have just left the salt off the top! Avoid crackers that are labeled "buttered," "rich," or those that are meat- or cheese-flavored. They are most likely higher in fat, sodium, and calories. Also, watch out for honey- or sugar-coated crackers because they are higher in calories.

Because crackers come in all shapes and sizes, the portion size for each type of cracker will be different. If you don't pay attention to the number of crackers in a serving, it can be very easy to eat too many and rack up the calories, causing weight gain.

Crackers can also add fiber to your diet, which is an extra bonus! If the list of ingredients on the box has "whole" grain flour as the first ingredient, you will be getting more fiber than if the flour is processed, refined, or enriched. Read the label!

The chart shows a sample of crackers that can be worked into a weight control diet on a daily basis. (Serving sizes are adjusted to provide 70-80 calories and may vary for different brands.)

Sample Snack Crackers	Number per Serving	Calories	Fat (grams)
Finn Crisp*	4	76	0
Ry Krisp, Natural* (whole)	4	80	0
Wasa Crispbread, Hearty Rye*	1½	75	0
Rice or popcorn cakes	2	70	0
Premium saltines (fat free)	6	70	0
Oyster and soup crackers	20	75	1
Snack Wells cheese crackers	22	75	1
Graham crackers (whole)	1¼	75	1
Orchard Crisps, low fat	7	70	2
Wheat Thins	8	70	3
Goldfish crackers, cheddar	25	75	3
Wheatables	6	70	3

*Note: Calories and fat vary for different brands. Read the Nutrition Facts label on your brand and adjust the serving size as needed to provide 70-80 calories.*

*\* These crackers provide 2 or more grams of fiber per serving.*



## The Chuckle Corner

At my house there are so many kids running around it is really hard to cut the extras out for the whole gang. So it is known that I don't care what the other kids snack on, BUT they are not allowed to eat in front of "KK," my 5-year-old son who is clinically diagnosed with PWS. They can hide in a closet or the bathroom—I don't care—just don't eat in front of KK. He even knows that the other kids get extra snacks and doesn't object unless he sees it happen. He

has told them on his own that they aren't allowed to eat in front of him, but then he will beg me for whatever they are eating.

One day we had extra muffins and my 6-year-old niece, Cassie, wanted one. I told her to hide in the corner of the kitchen where KK could not see her. He was on the Playstation and could have cared less. So she gets her muffin and heads for the playroom. I had to grab her and aim her for the corner to eat her muffin out of sight. When she finished she asked if my 5-year-old nephew could have one. I told her to tell him to come to the kitchen ... so she screams ... "Davey! Do you want a muffin?!!!" I clamp my hand over her mouth and tell her to not yell, to go tell Davey to come to me. So she goes to the playroom and yells again ... "Davey?! Do you want to eat a muffin where KK can't see you?"

At this point KK quits playing the game and looks her dead in the eye and says, "Cassie, me am fat, not can't hear!" He had me rolling LOL (laughing out loud). And they say children with PWS don't grasp the concept of sarcasm!

—Velma Jones



# A Grandmother's View

by Judith Diaz

I am the grandmother of Amanda Diaz, who is 5½ years old and has two brothers—Jason is 7 years old, and Adam is 11. A year ago I moved from California to Virginia. I felt that the family needed some support as they have no other family in Virginia (most of the family lives on the West Coast). I realized that in time Amanda would need more and more attention; with my being here, the family would not feel so isolated.

Since my arrival, my relationship with Amanda has become most loving and enjoyable. She in turn reciprocates demonstratively with love and affection. We enjoy doing things together. Amanda has been doing quite well this summer. She has been taking swimming and horseback riding lessons, which she enjoys immensely. She is such a joy with her spontaneous enthusiasm. Amanda enjoys helping her mother around the house and participating in family activities. The only difficulty is her uncontrollable appetite, which we try to curb, repetitive behavior, and compulsiveness. Amanda started kindergarten in September and is most enthusiastic about it.

I would like to be in touch with other grandparents to share ideas and experiences and learn from each other. If you wish to reach me, my e-mail address is [Jkario@aol.com](mailto:Jkario@aol.com), and my telephone number is 703-893-2048.



## Interested in connecting with other grandparents ... and helping PWSA develop a booklet just for grandparents?

Our Grandparent Project is off the ground! We've heard from more than 75 grandparent families who want to be included, and they will soon be receiving a questionnaire developed by Jim Gardner and Janalee. *You* can still be included!

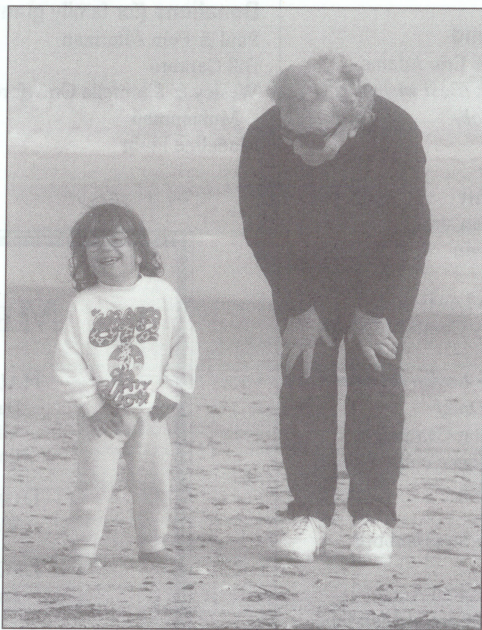
Just call or e-mail our national office and leave your name, address, and phone number. Tel.: 1-800-926-4797. E-mail: [pwsausa@aol.com](mailto:pwsausa@aol.com)

## New E-Mail Discussion List for Grandparents

If you're the grandparent of someone with PWS, and you'd like to talk with others through e-mail, there's a new discussion list just for you. It's the Prader-Willi-Grands Onelist, launched by the "super proud grandma of David," who is almost 5 and has PWS.

When you subscribe to a Onelist discussion group, you will receive e-mail messages—and can send messages to—everyone who's on that list.

To subscribe, send an e-mail to [Prader-Willi-Grands-subscribe@onelist.com](mailto:Prader-Willi-Grands-subscribe@onelist.com), or visit the Onelist Web site to sign up ([www.onelist.com](http://www.onelist.com)) and read the messages that have been previously sent to that list.



Judith and Amanda share a laugh at the beach.

## Looking for Pen Pals

*We've received the following requests for pen pal ads in recent months.*

### Erin, 34

"I am a 34-year-old lady from Arlington, Texas, between Fort Worth and Dallas. I was born with Prader-Willi syndrome. I volunteer at the local animal shelter two days a week and bathe the puppies and kittens and help out. I like bowling and doing crossword puzzles and the 1,000 piece puzzles you put together."

*If you'd like to be Erin's pen pal, you can write to her by either mail or e-mail:*

Erin Hendrix  
5600 Quail Lane  
Arlington, TX 76016  
E-mail: [erniemay@aol.com](mailto:erniemay@aol.com)



### Dauna, 28

"I live in Texas, near San Antonio. I would like a pen pal to visit with each day. I love fishing, drawing, camping, music, and school. I love to travel all over the world. I really would love to have some pen pals who have PWS."

*You can write to Dauna by e-mail:*  
[greeneyepd@aol.com](mailto:greeneyepd@aol.com)



### Heather, 22

"My name is Heather. I am 22 and I have PWS. I like the young country singer, LeAnn Rimes, and TY Beanie Babies. I would like both male and female pen pals."

*Heather doesn't have e-mail, but you can write to her at this address:*

Heather  
Davis Rd. ICF  
2206 Hillside Drive  
Corning, NY 14830





# Thanks to YOU ... we exceeded our goal for the 1998-99 Angel Fund Drive: \$75,108!

Contributions received in July and August are listed below.

## 1998-99 Angel Fund

### Heavenly Angel (\$500 to \$999)

Steve & Patti Tirney

### Arch Angel (\$250-\$499)

Ardis Burst

Al & Janalee Heinemann  
Russell & Catherine Mullis  
Robert & Julie Webster

### Angel (\$100-\$249)

David & Tammy Kenney (*in honor of Julia Kenney*)

### Cherub (Up to \$99)

Melvin Childress  
M. & S. Childress  
Criminal Investigation Division  
Groups 3 & 7  
First Congregational Church (*in honor of Peter Ingall*)  
Mary Ingalls  
Barbara Kenney  
Steven & Roberta Kenney (*in honor of Julia Kenney*)  
Robert Legendre  
Diane Rego  
Peter & Lucia Smith



## Other Donations

### Patron Memberships (\$100+)

Bill & Tina Capraro  
Julie Doherty  
Sybil Cohen Michael Burns  
Terry & Debbie Mieczewski  
Paul & Amy Wissmann

### Contributing Memberships (\$50-\$99)

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**Prader-Willi syndrome (PWS)** is a birth defect first 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. The 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.

