



# The *Gathered View*

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



Brittany Sharpe of Indianapolis, Indiana

**PWS Awareness Week is May 1 to 7**

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## Annual Conference Features Scientific and 'Hometown News'

Round up the family and head for the Sheraton World Resort in Orlando, Florida this summer. The theme for the July 27-29 event is "A Brand New Me," so get those cowboy boots ready for the best national conference east of the Pecos!

This year's Gala Banquet and Dance on Friday night will have live entertainment by the popular country western band and 2003 Academy of **Country Music Top Vocal Duo Nominee Hometown News!** They have found a heart for PWS, thanks to the Phernetton family of Indiana, and are donating their time for our conference. Hometown News will be singing their hit song "A Brand New Me" that will feature some very special lyrics. You can check out this dynamic singing duo on [www.hometownnews.info](http://www.hometownnews.info). Read more about Mickey and how Hometown News helped raise funds for PWS on page 14.

### **Outstanding Programs Planned**

July 27th will be a day of outstanding seminars for the scientific community, as well as programs for providers and chapter presidents. Our general conference program will have separate, age-appropriate sessions for parents and professional caregivers for children 0-5, school age, and adults.

We are again presenting "The Latest in Research" for all attending the general conference, plus a summary of the scientific presentations. Planned topics include: speech/language, behavior/medications, growth hormone in adults with PWS, respiratory/apnea issues, understanding IDEA, and guardianship/estate planning.

Additional options this year are several "sharing" sessions, including one for single parents and two for grandparents, grouped according to the age of their grandchildren. Our conference will include a Youth and

Mickey Phernetton, who has PWS, shown with the Hometown News, who will appear at national conference this summer in Orlando



Infants Program (YIP) for 0-5 as well as a Youth and Adult Program (YAP) for ages 6 and above. Siblings are welcome. Michelle Torbert and Michelle Holbrook will again direct the YIP and Tad Tomaseski will again direct the YAP. Tad plans an even more creative YAP program this year and will bring a group of trained volunteers to work with the program. The theme "A Brand New Me" also fits Tad's goal of focusing not just on fun, but also building self-esteem.

### **Convenient Location, Great Rate**

The Sheraton World Resort is within walking distance to Sea World and just minutes from Walt Disney World Resort and Universal Studio. The tropical-style resort has three outdoor swimming pools, a fitness center and lighted tennis courts. PWSA (USA) has secured a block of rooms at the discounted rate of only \$100 per night for up to four in a room. We have kept the discount

*Conference continued on page 14*

# Prader-Willi Syndrome Association (USA)

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## NEWSLETTER

Jane Phelan, Editor  
Lota Mitchell, Associate Editor

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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) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

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**Our Mission:** Through the teamwork of families and professionals, PWSA (USA) will improve and enhance the lives of everyone impacted with Prader-Willi syndrome (PWS) and related conditions.

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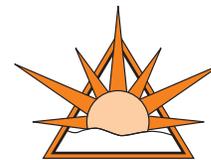
### Liaison Members:

Ken Smith, The Children's Institute, Pittsburgh, PA  
Suzanne Cassidy, M.D., Scientific Advisory Board, U.C.I. Medical Center, Orange, CA  
Janalee Heinemann, M.S.W., Executive Director, PWSA (USA), Sarasota, FL

**Deadline to submit items for upcoming issues of *The Gathered View***  
Jan/Feb: Dec 1; Mar/Apr: Feb 1; May/Jun: Apr 1;  
Jul/Aug: Jun 1; Sep/Oct: Aug 1; Nov/Dec: Oct 1

**Members Only:** Check our PWSA (USA) web site for Special Opportunities Limited to Members: [www.pwsausa.org](http://www.pwsausa.org)  
User Name: members; Password this issue is BRAND  
If asked for Domain Name it is CIMCO

# 2005 Nominees to the PWSA (USA) Board



By Lisa Graziano, Chair, Leadership Development Committee

Although PWSA (USA) President Carolyn Loker's Board term is up and she would have to run again to keep her board position, she has decided not to run. Carolyn believes all of the candidates are so outstanding that she would not want PWSA (USA) to risk losing any of them as active board members.

Carolyn will continue to do all she is doing, and states, "This has been an outstanding board, and adding Bill Capraro to the board will make it even more so! I look forward to working with each and every person in the years to come."

## **There are four openings on the Board of Directors. The nominees are:**

### **Janice M. Agarwal, P.T., Zionsville, Indiana**



Janice has 15 years of pediatric physical therapy experience, with emphasis on young children from birth to age 3. She uses both Neurodevelopmental Training (NDT), certified in 1995 by the Bobath Centre in London, England, and Sensory Integration (SI) techniques. She was part of the neurodevelopmental evaluation team at Boston City Hospital and the early intervention team at St. Mary's Hospital for Children in New York. She has lectured on infant development and therapeutic intervention for hypotonic children for therapists in New York and for therapists and parents at PWSA(USA) national and IPWSO international conferences. A former PWSA (USA) board member, Janice has written articles for The Gathered View. The mother of Alexander, 5, who has PWS; and Samuel, 4, Janice also mentors parents of young children with PWS. "We need to educate each other using our individual areas of expertise," she writes. "I want to bring both a therapist's and a young mother's perspective to the Board."

### **William Capraro Jr., Oak Brook, Illinois**



Bill Capraro has been committed to PWSA (USA) since his daughter Lea, now 9, was diagnosed with PWS 2 months after birth. Bill and his wife Tina have three children: Will, 11; Lea and Tori, 7. They have taken active roles as parents of a child with PWS to help support research and improve the lives of children with PWS. Most recently, the Capraros hosted two record-setting fund-raisers, the latest raising donations of more than \$95,000. It's the largest fund-raiser ever hosted by a PWS family in the 27-year history of PWSA (USA). Bill founded CIMCO Communications, a data and voice communications company, in 1985. He holds an MBA from Northwestern University's Kellogg Graduate School of Management. As CEO of CIMCO, Bill is active in telecommunications organizations as a voice for companies trying to compete in a highly monopolized industry. Similarly, Bill uses his passion, enthusiasm and influence to ensure that PWS children like Lea have the same support and opportunities as other children.

### **Carol Hearn, Plymouth, Minnesota**



Carol is a graduate of Harvard Law School and has practiced law in Minneapolis, Minnesota for the past 20-plus years. She and husband Tim have three children: Jessica, 18; Maryellen, 16; and David, 12, with PWS. She writes, "When David was born in 1992, we were obviously concerned about what disability he had and what the future held for him.... I found myself focusing each day on what he *could* do rather than what he couldn't do, with the result that I have been able to enjoy him and his accomplishments from a unique perspective. He is the most joyful person I have ever met, and I learn something new from him every day."

A board member and past president of PWSA of Minnesota, Carol is currently chair of the PWSA (USA) board. She writes, "I am constantly amazed at what this organization is able to accomplish with such a small staff and such limited funding. Their dedication, and that of the officers, board, medical professionals and other volunteers is truly awe inspiring. If re-elected to the board I hope to build upon the energy and enthusiasm of this remarkable team effort."

### **Ken Smith, Pittsburgh, Pennsylvania**



Ken is currently manager of the Prader-Willi Syndrome/Behavioral Disorders Program at The Children's Institute in Pittsburgh, Pa. The Institute has served approximately 1,000 children and adults with Prader-Willi syndrome and related disorders over the past 22 years. Ken has worked at the Institute for 20 years, 3 in direct care and the rest in various administrative roles.

Ken has previously served three terms on the PWSA (USA) Board of Directors and was board chair for 3 years. He writes, "I sincerely believe that PWSA (USA) is an extraordinary organization and I would be honored to serve for another term on the Board."

**Prader-Willi Syndrome Association (USA) 2005 Official Proxy**  
**Must be received at PWSA (USA) office by July 15, 2005**

I hereby appoint \_\_\_\_\_ of \_\_\_\_\_  
(print name of your designated proxy voter) (state of residence)

to vote as my proxy at the PWSA (USA) Annual Membership Meeting in Orlando, Florida, July 2005.

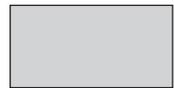
**Instructions to proxy voter:**

- Please cast my vote as you see fit**      **OR**       Please cast my vote for the Board of Directors candidates I've marked below: (VOTE FOR 4)
- I am a member in good standing of PWSA (USA)       Janice Agarwal
- Name \_\_\_\_\_       Bill Capraro  
(please print)       Carol Hearn
- Signature \_\_\_\_\_       Ken Smith
- Date \_\_\_\_\_       \_\_\_\_\_  
(This space provided for a write-in candidate)

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Prader-Willi Syndrome Association (USA)

This ballot to be  
used by Family  
Memberships only



I hereby appoint \_\_\_\_\_ of \_\_\_\_\_  
(print name of your designated proxy voter) (state of residence)

to vote as my proxy at the PWSA (USA) Annual Membership Meeting in Orlando, Florida, July 2005.

**Instructions to proxy voter:**

- Please cast my vote as you see fit**      **OR**       Please cast my vote for the Board of Directors candidates I've marked below: (VOTE FOR 4)
- I am a member in good standing of PWSA (USA)       Janice Agarwal
- Name \_\_\_\_\_       Bill Capraro  
(please print)       Carol Hearn
- Signature \_\_\_\_\_       Ken Smith
- Date \_\_\_\_\_       \_\_\_\_\_  
(This space provided for a write-in candidate)



## Executive Director's View

# A Tribute to Our Very Generous Physicians

Janalee Heinemann

You often hear stereotypes of physicians raking in the money and spending afternoons on the golf course. But those are not the medical professionals I know!

The PWS physicians I know are not only *not* on the golf course, they are working late into the night writing medical briefs and responding to e-mails after a busy day at clinic or in the lab. They are also *not* charging for every 10 minutes of their time, but instead donating hundreds of hours of time to PWSA (USA).

In fact, some of the most valuable donations of time to our organization are the many, many hours donated by our two medical boards, the Scientific Advisory Board (SAB) and the Clinical Advisory Board (CAB).

Every day I am communicating with one or more members of the SAB and CAB. Reviewing research grants is just a very small component of the donated hours from the SAB. Both

the CAB and SAB respond to medical and

**How can we appropriately thank the experts who have saved so many lives through their selflessness?**

research questions we send by e-mail, consult with other physicians, write articles and chapters for our books and newsletter, edit others writing for our books, chair and prepare for our conferences, and attend and speak at many of our meetings at both a state and national level.

To give you an appreciation of what this means in terms of free services for national organization and our PWS families, just look at the chairs of our two medical boards, **Dr. Merlin Butler** and **Dr. Dan Driscoll**. Between them, they donated more than 700 hours in 2004 alone. The value of this donated service is estimated at more than \$200,000!

Not all of the CAB and SAB have been able to dedicate this extensive amount of time, but all give more time than most of our members can truly appreciate. Because I work very extensively with our medical boards, I *do* appreciate all they do — every single day, so I want to publicly thank all 24 members for their irreplaceable gift of time and knowledge.

I know of the many, many hours **Dr. Phillip Lee**, **Dr. Merlin Butler** and **Dr. Barb Whitman** have put into editing our upcoming 3<sup>rd</sup> edition of the Management book. I also know of the hours **Dr. Moris Angulo** has spent writing and translating medical information into Spanish, and **Dr. Ann Scheimann** and **Dr. Jim Loker** have donated by consulting with many, many physicians on GI and cardiac

crises — including allowing us to page them in an emergency.

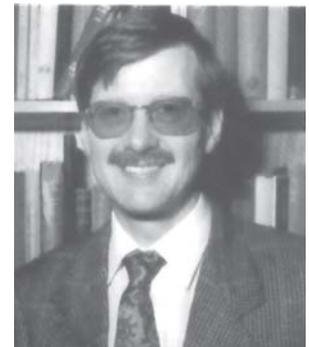
Then there is the time donated by physicians involved with our study on deaths, and the time spent writing medical articles for our publications.

Also, if it were not for our endocrinologists who have been willing to consult with other endocrinologists on growth hormone, and the physicians who have helped us with the respiratory and growth hormone concerns, we could have lost one of the best therapeutic drugs for PWS.

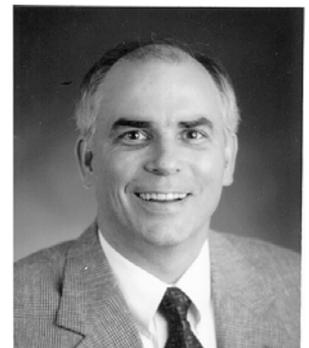
I do not want to forget Dr. Lee's amazing and extensive responses via e-mail, **Dr. Hainline**, **Dr. Driscoll** and **Dr. Butler's** frequent responses on genetics and other issues, **Dr. Suzanne Cassidy** and **Dr. Jeanne Hanchett** for their many, many years of wise consult and donated services, **Dr. Linda Gourash** and **Jan Forster** and all of their consults on serious psychiatric and weight management issues. (Note: Dr. Forster is not on our boards, but still donates her time and expertise, as has **Dr. Shawn**

**Between them, Dr. Dan Driscoll and Dr. Merlin Butler donated more than 700 hours in 2004 alone.**

How can we appropriately thank the experts who have saved so many lives through their selflessness? There are no adequate words. There is no adequate way. I do want them to know that we know that we could not do what we do without them!



Merlin G. Butler, M.D., Ph.D.  
Chair, Scientific Advisory Board



Daniel J. Driscoll, Ph.D., M.D.  
Chair, Clinical Advisory Board

**McCandless**, who chaired the 2004 conference.) And these are just a few people and projects that come to mind.

How can we appropriately thank the experts who have saved so many lives through their selflessness? There are no adequate words. There is no adequate way. I do want them to know that we know that we could not do what we do without them!



## Dedication Even in Retirement

Carolyn Loker

When you ask Barb McManus why she spends so much of her time involved with PWSA (USA), her response will always be, "It is my mission to help my granddaughter Jessika, her family, all individuals with PWS and their families."

Barb first began as webmaster, served 3 years as secretary for the board of PWSA (USA) and is currently coming up on her third year on the Board of Directors.

When most of us think of retiring, we think of having fun with friends and family, traveling or just relaxing. When

Barb thought of retiring, she stated, "Now I'll have more time to be involved with PWSA (USA)."

A reminder of that was reinforced as I was leaving the recent Board of Directors meeting in Sarasota. Barb and her husband Mike had been in Sarasota for two weeks to help at the national office. Looking at the beach just across the road, I asked Barb, "How many times have you walked on the beach just to relax?"

Her response was, "Twice, I have too much work to do!"

This is just a constant reminder of dedication as we all work together toward our goals.

## Using Computer Skills On Behalf of PWSA (USA)

By Barb McManus

Jessika Dickinson was born March 24, 1992. She was my first grandchild. It wasn't until 3 or 4 years later that her mother (my daughter Jeannie) and I found out Jessika had Prader-Willi syndrome. I set up a webpage about Jessika when she was 6 years old where my daughter wrote telling everyone about our little angel, who, hard to believe, became a teenager this year!

A wonderful mom with two younger daughters, Sari, 7, and Isabel, 5, Jeannie manages a busy life with her husband Tom and the three girls, along with being a personal chef for another family. Her time is well spent and I am very proud of her.

I have made it my mission in life to do all I can for Jessika by using my talents to help PWSA (USA) and Prader-Willi Alliance of New York. Those talents are computer-related; therefore I am the webmaster, database coordinator and office technology consultant for PWSA (USA) and webmaster for the New York Alliance. I am also a board member in both organizations. I have been handling the national conference registrations for the past few years and I wrote the booklet, "My Grandchild has Prader-Willi syndrome... Now What?"

All of this has kept me so busy that I recently retired from my technical position at our local university to do this work full time. In this article I focus on two of my projects: the web site and updating the national database of people with PWS.

### Our web site

The PWSA (USA) web site has evolved over time. We now have updates going on the site every day. Sometimes I spend an entire day working on the site. Soon we will have an improved Members Only section where you can enjoy news before it appears on the main website, along with other

important features available only to members. The first page will change periodically, showing different pictures of our families. You will find information about upcoming conferences, local events and fund-raisers going on around the country.

### Improving our Database

Updating our database of people who have PWS is a major undertaking begun about 2 months ago. The project is supported by funds designated for this project. You do not need to be a member of PWSA (USA) to participate in the collection of information. I took on this task because I know that together we can make a difference.

In the last issue of *The Gathered View* we published an article about the database project and recently sent letters requesting information to the last known address of the primary care person. We are very pleased with the responses, which are coming in by mail and through the web site every day.

There may be some confusion about the address on the questionnaire. I live in Niagara Falls, New York, which is why the mailing address for this survey update is mailed to P.O. Box 1114, Niagara Falls, NY 14304-1114. This address is for the survey only — nothing else.

When I receive survey replies, I enter them remotely on the database located in Sarasota, Florida.

Barb McManus wants YOU to complete the PWS database!



Computer continued on next page

Our goal is very ambitious: we hope everyone who has been diagnosed with Prader-Willi syndrome will be identified through this process.

However, many letters have been returned because of incorrect addresses. Please help us locate others with the syndrome. Please contact everybody you know who cares for a person with PWS and ask if they have filled in a survey for PWSA (USA). The survey can be downloaded in paper form and mailed to me in Niagara Falls or filled out online at <http://www.pwsausa.org/population>.

### The larger our numbers ~ the louder our voice

The information collected will be useful in so many ways. The PWSA (USA) office is often asked for statistical information about our population. For example, by collecting the height, weight and age of people with PWS, we could calculate body mass indexes (BMI) on the population we have identified. The results may show that we are managing the weights of those with the syndrome. Perhaps we can identify possible health risks related to one of the traits noted on the survey. We can collectively identify key areas where further research is needed. In the past, it has been difficult to supply researchers with information that we as parents and families believe is important.

I will continue to keep our database up-to-date! A process will be designed so you can update your information through a web page. It will be set up in a secure manner using a record ID and the date of birth of the individual. When the system is ready, it will be announced on the front page of the PWSA(USA) web site: <http://www.pwsausa.org>.

We'll also attempt to keep those who don't have internet connections identified and current in the system through periodic telephone calls and mailings.

At a later date, collection of other information may become necessary. For example, if we need to know more

**CALL FOR SCIENTIFIC PAPERS**  
**Prader-Willi Syndrome Association (USA )**  
**Annual Conference**  
**July 27, 2005- Scientific Day**

**Please submit the following information by April 1, 2005 and submit your abstract by April 15, 2005:**

Name, address, company, affiliation, telephone, fax, e-mail, title of abstract for presentation (if known), area of research (More than one abstract may be submitted; circle all that apply):

Genetics \* Medical \* Nutrition \* Behavior \* Obesity \* Neurology \* Social \* Endocrine \* Other (list).

Your abstract will be limited to one page, single-spaced, with margins of approximately one inch, and a minimum type font size 12. It is our goal to have the abstracts published. Full details, including an example abstract form, are available at the PWSA (USA) website, [www.pwsausa.org](http://www.pwsausa.org), and the national office. Notification of acceptance will be provided by May 1, 2005.

**Please send this intent form, and later your abstract, to:**

**Merlin G. Butler, M.D., Ph.D., Scientific Chair**  
**by e-mail at [mgbutler@cmh.edu](mailto:mgbutler@cmh.edu)**  
**or by fax to 816-346-1378.**

about our older population, we can ask for information regarding only them — no need to collect that information from everyone. But if we don't know who you are or where you live, we cannot have your participation.

If you want to update your information, write to me at Niagara Falls, N.Y. or e-mail [www.pwsausa@pwsausa.org](mailto:www.pwsausa@pwsausa.org). Everyone who completes a form will receive a copy of our new Medical Alert Booklet, which is essential for doctor and emergency room visits. We are in this together, and together we will be heard.

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## Chapter View

A very big **THANK YOU** to the chapters that supported National in 2004! Special recognition goes to **Maryland, Florida, New Jersey, Ohio, Minnesota, Georgia, Colorado, Wisconsin, Pennsylvania, Ohio Families, Michigan, California, and Maryland/Virginia/DC.** Several responded to the appeal for help with operating funds made by our Chair of the Board Carol Hearn in the September/October issue of *The Gathered View*. Others sent financial support to national during the year for conference, 10% of fund raising, conference grants, or simple contributions. We express appreciation to them also on behalf of our membership, which benefits both directly and indirectly from that so important financial help to national to assist it to continue to operate and provide all its many services.

We're happy to welcome **PWSA of Pennsylvania's** new president, Debbie Fabio. After traveling the world as a travel

agent for 18 years, she now works in Customer Service for Parks and Recreation for Cranberry Township, where she lives. She plays clarinet in her community choir along with daughter, Danielle, 13; participates in her church's hand bell choir and helps with the youth choir. Son Stephen with PWS, 10 ½, is atypical. He has the behavior issues, but needs to gain weight! He has unspecified colitis, which causes upset if he eats very much. Husband Mike is co-chair of the chapter's annual golf outing, coming up for the sixth time on May 25.

**PWS Arizona Association** had a Prader-Willi Mini-Conference on Jan. 29, sponsored by Phoenix Children's Hospital and Pfizer. Topics included growth hormone, genetics, pulmonary aspects of PWS, and nutrition. Meetings of this type are of great benefit for those with time or money issues that prevent them from attending the national conference. — **Lota Mitchell, Associate Editor**

# The Genetics of Prader-Willi Syndrome: *An Explanation for*

By Linda Keder

*Part 2 of 2. Linda Keder, former editor of The Gathered View, originally published this article in the March-May 2000 issue. It was revised and updated in July 2004 with the assistance of Merlin G. Butler, M.D. Ph.D., who chairs the PWSA(USA) Scientific Advisory Board.*

## Genetic Tests for PWS

Because the genetics of PWS is so complicated, it usually takes more than one test to be certain whether someone has PWS and what form of it they have. The major tests that are used in the diagnosis of PWS are shown in the table below. Which genetic tests are used, and in what order, will depend on a number of considerations for each individual case (see Testing Considerations). Genetic testing usually requires a blood sample from the child and possibly from the parents as well.

Families should consider genetic testing for PWS if they have:

- a baby with low muscle tone (hypotonia), poor sucking ability, and — if a boy — undescended testicles;
- a child or adult who has a number of the characteristics of Prader-Willi syndrome as listed in the Diagnostic Criteria for PWS ([www.pwsausa.org/syndromeDiagnos.htm](http://www.pwsausa.org/syndromeDiagnos.htm)); or an undiagnosed child who was tested for PWS using older tests than those available today.

## Testing Considerations

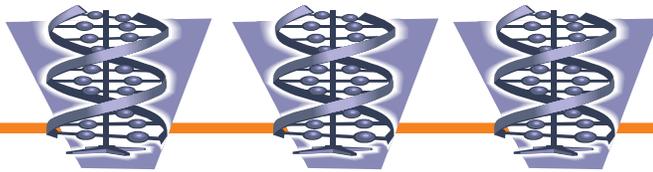
**Which genetic tests should be done and in what order?**

The approach to testing for PWS in any given case will depend on a number of considerations — what tests have already been done, what expertise and laboratories are available, whether both parents are available for blood samples, and so forth. Chromosome studies are typically done in any case, but the order of the other tests — and their results — will determine how

*Genetics continued on next page*

## Genetic Tests Used To Diagnose Prader-Willi Syndrome

TEST	WHAT THIS TEST DETECTS	WHAT IT <u>CAN'T</u> DETECT	TEST AVAILABILITY
High resolution Chromosomal Analysis(examination under a microscope)	Large deletions and other chromosome abnormalities such as translocations and extra chromosomes	Small deletions, Uniparental disomy (UPD) Imprinting defects	Widely available
FISH (stands for <i>fluorescence in situ hybridization</i> , often done at the same time as a chromosome analysis)	Deletions of <i>all</i> sizes	UPD, Imprinting defects, Which parent each chromosome 15 came from (A deletion could mean either Prader-Willi or Angelman syndrome.)	Widely available
<i>The following are classified as "molecular" tests:</i>			
DNA methylation test(confirms or rules out PWS as a diagnosis, with over 99% accuracy)	The imprinting pattern in region 15q11-q13 (Normal results show both paternal and maternal DNA pattern. In PWS there is only a maternal pattern, whether there is a deletion, UPD, or imprinting defect.)	Which form (molecular class) of PWS the child has: deletion, UPD, or imprinting defect	Not widely available
DNA polymorphism studies (done to detect UPD, requires blood samples from both parents and child for best accuracy)	Which parent each chromosome 15 came from (If both chromosomes are from the mother, the child has PWS; if both are from the father, it's Angelman.); can also detect some deletions	Imprinting defects, Some deletions	Not widely available



many need to be done. In 1996, two national genetics groups worked together to develop guidelines on testing for Prader-Willi and Angelman syndromes. Their recommendations have been published and are available on the Internet at [www.faseb.org/genetics/acmg/pol-22htm](http://www.faseb.org/genetics/acmg/pol-22htm). In most cases, they recommend continued testing until the genetic cause of PWS is known.

### Some testing scenarios:

- If an experienced diagnostician suspects Prader-Willi syndrome in an older child or adult who meets the Diagnostic Criteria for PWS, the FISH test might be the first test of choice because it is widely available and will detect the majority of cases of PWS. If the FISH test is positive (a deletion is found), the diagnosis of PWS is confirmed and no further testing is needed. If the FISH test comes back negative (detecting no deletion), the next step would be the DNA methylation test. A relatively new test, DNA methylation can diagnose more than 99 percent of people with PWS, but it does not tell whether the cause of PWS is deletion, uniparental disomy (UPD), or an imprinting defect. If, after the negative FISH test, the methylation test confirms that the person has PWS, more testing is needed to find out whether the cause is UPD or an imprinting defect. If the UPD test is negative in this case, the cause *must* be an imprinting defect. At this time, imprinting defects are diagnosed by process of elimination — positive methylation test, but negative FISH and UPD tests — however, to confirm a suspected defect may require testing in genetics laboratories specializing in PWS research.

- In cases where the suspicion of PWS is not as strong, or where the diagnosing physician is not as familiar with PWS, the DNA methylation test might be the best place to start. The test is becoming more widely available

and can confirm or rule out PWS at the first step. If the methylation test is positive, then additional testing can be done at the same lab to determine the specific form of PWS. Even experienced diagnosticians have sometimes misdiagnosed infants as having PWS when in fact they had Angelman syndrome. (Both syndromes can cause hypotonia in the newborn baby, and both will show a chromosome 15 deletion on the FISH test.) Starting with the methylation test avoids this problem.

In cases of an imprinting defect or other rare test findings, families may need further testing through a research laboratory, both to get an accurate diagnosis and to learn about their risks of having another child with PWS.

### What about prenatal testing?

Prenatal testing for PWS is now available. An expectant family might wonder whether to have testing done if they have had a child with PWS previously. Although the risk of having a second baby with PWS is very low in most cases, prenatal testing can provide important reassurance to the family that the new baby will not be affected. Counseling by a genetics professional can help a family understand their specific risks and whether testing of the fetus is important in their situation.

Prenatal testing for PWS might also be done in cases where a genetic study of the fetus (through chorionic villus sampling — CVS — or amniocentesis) shows abnormalities that raise suspicion of PWS. In one case, for example, a routine chromosome test done through CVS early in a woman's pregnancy found that *some* of the baby's cells had three chromosome 15 (called *mosaic* trisomy 15). This led the doctor to order a molecular test for maternal uniparental disomy (UPD) in the remaining cells. Results showed the baby would have PWS due to UPD.

### Who should do the testing?

Families who are seeking a diagnosis or who have concerns about their risks should work with a genetics specialist who is knowledgeable about PWS and the latest in testing. The geneticist will arrange to have blood samples sent to an appropriate laboratory for testing.

There is available on the Internet a free, searchable database of genetics laboratories and the tests they offer for specific conditions such as PWS. GeneTests Laboratory Directory (formerly called Helix) is sponsored by the Children's Health Care System, Seattle, Washington, and can be found on the Internet at [www.genetests.org](http://www.genetests.org). Note, however, that not every laboratory that performs these tests is included in the database.

Those who need help in locating a geneticist or a testing center may contact the PWSA(USA) national office at 1-800-926-4797 or through its Website, [www.pwsausa.org](http://www.pwsausa.org).

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*The author thanks Drs. Suzanne Cassidy, Dan Driscoll and David Ledbetter for editing the original article, and Dr. Merlin Butler for assisting with this latest revision.*

## A Whole New Life For This Family's Cat

By Lisa Peters

My son Nicholas is almost 3 years old. He was diagnosed at birth with PWS. Since that time, we have had him evaluated by the finest doctors. We have had him enrolled in the best therapy programs available. We started him on GH, vitamins, CoQ10. He's had g-tubes and AFO's.

And while all of these interventions have been very important, I can tell you without a doubt that the biggest inspiration to Nicholas has been the family cat, Bandit.

This poor fluffy fellow is almost solely responsible for my son's daily exercise program of walking, talking, jumping and most importantly, laughing.

Yes, life has certainly changed for Bandit since Nicholas joined our household. Bandit's once leisurely lifestyle has been transformed into a rigid regime of hard-core therapy for Nicholas. He is chased. He is massaged. He is harassed and cajoled. He has even sourly withstood a haphazard baby-carriage ride around the kitchen (blanket and all).

But I think by far Bandit's bravest contribution was when my son began to learn to walk.

Nicholas did not have the strength and coordination to walk by himself. His mind was eager to explore, but his poor little body could not manage the task. He had taken a few good spills and was reluctant to try again. Our PT brought us a walker and suggested he try it.

Well, I cried and cried at the sight of this metal monstrosity. It was ugly and institutional-looking. But my tears of sadness were quickly replaced with tears of joy when I saw what happened next. My son's eye's started to sparkle when he saw this shining chariot. He grabbed the handles,

spun it around and headed immediately for the cat. He still couldn't talk, but the look on his face screamed, "Aha, now I've got you!"

This was not a "walker" to Nicholas. To him it was the coolest cat-chasing machine known to man.

Well this poor cat nearly jumped out of his fur when he saw the silver streak barreling down on him.

SCRAAAAATCH went the sound of the metal legs sliding across our kitchen floor.

And like Tarzan from the Jungle, "AAAAH-EEE-AAAHH-EEE-AAAAHHH!" came roaring from Nicholas's mouth!

Since that day, my once docile cat now sits steadfastly alert, waiting for his next therapy session.

And like a GPS tracking device, be it day or night, my son Nicholas can tell you exactly where you can find Bandit.

*Lisa Peters lives in Georgetown, Massachusetts.*

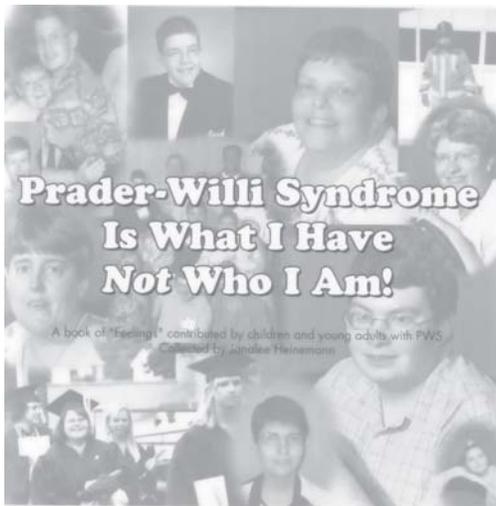
Bandit the cat now gets energetic daily exercise with Nicholas, 3, who has PWS



## Prader-Willi Syndrome Is What I Have Not Who I Am!

Author Janalee Heinemann

Rated Q\* - Recommended for Teens and Adults with PWS and their Parents and Caregivers



Our heart-warming new 70-page book is the *first ever* collection of writings by people with the syndrome – for others with the syndrome – and for all who want to understand what it is like to live with the syndrome.

It is a window into the feelings of all of our young people with PWS – and a light reflecting all of their beauty and courage. This book will be appreciated by all older children and adults with the syndrome, and is a "must" for all caregivers of our older children, providers, and teachers.

Cost is \$10 for members and \$15 for non-members. Call our PWSA (USA) office at 800-926-4797 to order or go to our web site, [www.pwsausa.org](http://www.pwsausa.org).

*\*Rated "Q" This qualified rating is given because the material may have disturbing aspects which (a) do not apply to a young child, and/or (b) may never apply to a particular child because of research advances or the child's own development.*

## View From the Home Front

# From 'Tragedy' Comes Friendship and Enlightenment

By Rebecca Loupe

My son Austin is 4 months old, and he was diagnosed with Prader-Willi at 3 weeks. Our story is the same as all the other parents who have a child with PWS. We were devastated at the news. I actually found out the results when my husband was offshore. I had to keep the news from him until he came home 5 days later.

God is so good. My husband took the news pretty well. He asked me, "Would you love him any differently if he were normal?" Of course my answer was no. It makes all the difference in the world to have a husband with so much compassion. But it doesn't take away the fear of what the future will hold for our family.

My story has an awesome twist as to how God puts people in your life to help you get through the darkest moments. You see, Austin has been receiving physical therapy and occupational therapy through a local early intervention program called Early Steps.



Austin Loupe, 4 months, and Allison Desmore, 5 months, who both have PWS.

A few weeks later, I received a call from a lady named Holly telling me she got my number from her daughter's physical therapist. I was so excited to get her call. We finally had someone who truly understood what we were going

through. We talked for an hour. She told me that her daughter had been diagnosed with PWS the day before. She lives only about 30 minutes away. We met the day after our phone conversation. Now we visit each other at least once a week. We have become really good friends through the disability of our little angels. Our older children love getting together too. Life is so good. Sometimes tragedy can make you see things in a different light. Sure, we could take what God has given us and cry about it. Instead, we look at it with a positive attitude and make the best of it. I couldn't imagine my life without Austin. We are truly blessed.

*Rebecca and Jason Loupe live in Lockport, Louisiana.*

## Studying Behavior and Medication in Those With PWS

Dr. Elisabeth Dykens' research team has been awarded a grant by PWSA (USA) that should lead to better understanding of the medications used to treat maladaptive behaviors in PWS.

Many people with PWS struggle with maladaptive behaviors that overshadow their personality strengths and impede their optimal functioning. When symptoms do not respond to the usual behavioral interventions, some people with PWS respond well to medications, including the widely-used selective serotonin reuptake inhibitors (SSRIs) such as Prozac or Zoloft. While medication may help some people with PWS who have fewer or less severe compulsions, skin-picking or tantrums, other people do not show such positive responses, and still others are made worse.

Why is there such variability in how people with the same syndrome respond to the same medication? A new way to answer this question comes from the field of pharmacogenetics. Pharmacogenetics seeks to link genetic differences in drug metabolism with variability in drug response. Although much work remains to be done, genetic differences have been identified in how people metabolize or break down SSRI's and other psychotropic medications. These studies are particularly well-justified in PWS, as people often have a

predictable set of symptoms, such as irritability and compulsions, along with variable responses to SSRIs and other medications.

We plan to recruit 200 people with PWS (with either UPD or deletion), ages 8-59, both males and females, who have been treated or are currently being treated with psychotropic medications for behavioral or psychiatric symptoms.

We want to learn more about the whole range of possible responses, from very successful to adverse. Questionnaires will address maladaptive behavior, psychiatric symptoms and parent coping skills, as will medication use, dosage and symptom relief. A genetic sample will be collected using cheek cells from two mouthwash samples that will be included with the questionnaires.

Ultimately this work will lead to more effective medications based on individual differences within PWS.

For further information call Research Coordinator Elizabeth Roof at 615-343-3330 or e-mail at [Elizabeth.roof@vanderbilt.edu](mailto:Elizabeth.roof@vanderbilt.edu).

*This grant has been funded by PWSA (USA) through the Friends of Lea Capraro Fundraiser and the Valentine Research Fund Campaign.*

## Board of Directors View

# Moving Ahead With Confidence and Enthusiasm

By Carol Hearn, PWSA (USA) Board of Directors Chair

I am pleased to report that the PWSA (USA) Board of Directors had a very productive set of board and committee meetings in Sarasota on January 21-23, 2005. Here are the highlights.

We welcomed two great new members to our working team: Jodi O'Sullivan, PWSA (USA)'s new part-time director of community development (read more about Jodi below); and Julie Doherty, the new secretary of PWSA (USA). Each of these women has a niece or nephew with PWS, and brings to her new position an ideal combination of excellent skills and passion for the job.

Thanks to the tireless efforts of our treasurer, book-keeper, business manager and the Finance Committee, we were able to review PWSA (USA)'s unaudited financial statements for 2004 just a few short weeks after the close of the fiscal year. In addition, thanks to new grassroots fund-raising efforts by several families and some generous (and unanticipated!) individual gifts, it looks as though we closed out the year with a better financial picture than we had expected. We still have a long way to go before we can consider PWSA (USA) financially secure, but we can at least breathe a bit easier in the short term.

We received updates on the recent activities of our various committees and project teams. Meeting in committees, we began developing action plans for accomplishing specific short-term and long-term goals. Some of our biggest challenges (and potentially most exciting opportunities) lie in the following areas:

### Conference

Virtually every staff member, officer and board member of PWSA (USA), together with countless other volunteers, is involved in the planning and implementation of the upcoming annual conference in Orlando in July, 2005.

Plans are also under way for the 2006 conference, tentatively scheduled for New York near Niagara Falls.

### Fund Development:

Raising the money necessary to keep PWSA (USA) operating and sustain our conferences, research, crisis, mentoring, educational outreach and other vital programs is the least glamorous but most important part of our job as a board.

PWSA (USA) is thrilled to have Jodi O'Sullivan on board. She will be instrumental in helping the Fund Development Committee and our members, volunteers and supporters in their collective efforts to raise funds and awareness. Currently, we are involved in a number of fund-raising activities throughout the country — from golf tournaments to walk-a-thons, from silent auctions to a new Prader-Willi Syndrome Association calendar. We are covering a number of bases in order to make fund-raising fun, easy and productive. Also, we are planning some interesting projects at the National Conference in July. Please feel free to call the

national office at 800-926-4797, and we will help you through the steps necessary to organize an event in your community. We appreciate all your effort and support, and we pledge to offer whatever assistance we can to help you host a first-class event in your area.

### Research

The board recently funded a number of research projects, including PWSA (USA)'s database project, a project to study deaths of people with PWS, and a study of the effectiveness of certain psychotropic medications.

We also sponsored a roundtable discussion of PWS research professionals who met in Baltimore in November.

Based, in part, on the consensus of the roundtable participants, the board has now authorized the Research Committee and the Executive Director to seek expressions of research interest in the following areas: gastrointestinal issues and concerns in people with PWS; respiratory issues/concerns in those with PWS; and therapies for hyperphagia in PWS. These important new initiatives will require a redoubling of our efforts to raise money for research.

### Crisis Counseling

PWSA (USA)'s crisis counseling program provides critical information and support to those in medical, educational and legal crises. Given the ever-growing demands of the program, it is clear that PWSA (USA) will need to retain a well-qualified, full-time professional to replace our current part-time crisis counselor David Wyatt when he retires in July 2005.

You would think that 2½ days of board and committee meetings would be a draining experience, but I have to tell you, it was positively invigorating! The energy and enthusiasm of this fine group of people was apparent throughout the weekend. We have set for ourselves some ambitious goals, but I am confident that, with help from our members, we can achieve them.

## The Chuckle Corner

### From the Mouths of Babes...

A beloved former teacher and her daughter stopped by unexpectedly for a visit. They gave Erin a cute Beanie Baby dog, and just when I thought she was going to thank them, she held it up and said, "Well, Mom, here's just one more thing that we don't need." I prayed for the floor to open up and take one of us. It didn't really matter which one! Fortunately, her teacher just cackled, and we have yet another story to add to Erin's saga. Oh, this child!

*Rachel Tugon, Louisville, Ky.*



# Estate Gifts Build Brighter Future for Those With PWS

By Stephen Leightman, Fund Development Committee Chair

## The Past

Last summer *The Gathered View* contained a thought-provoking article by the chair of PWSA (USA)'s Board of Directors. She cited the financial crisis facing our organization and challenged us to face our fiscal reality and to commit to our future.

Thanks to the tremendous effort by our dedicated staff, core of volunteers and supporters, we were able to complete 2004 without incurring an operating deficit and without having to cut back on any of our services. One element that gave us a significant boost was a generous bequest to our Association left by the estate of a family that PWSA (USA) has helped in the past. This gift, along with others, made it possible for the Board to authorize two research grants designed to advance our pursuit of answers to many of the questions that are inherent in better understanding the syndrome.

**There are many ways to help us make sure our work can continue now and in generations to follow.**

This generosity took many forms: fund-raisers, cash donations, grants, gifts of appreciated stock, and a significant testamentary gift.

## The Present and Future

Now that we have met our current shortfall, our concern turns to the present and the years ahead. There are many ways to help us make sure our work can continue now and in generations to follow. In this article, we will focus on estate gifts.

Using estate gifts (i.e., wills, bequests) can help us seek brighter futures for both adults and children afflicted with Prader-Willi. By including PWSA (USA) in your estate plan, you can play a major role securing our ability to serve our population, educate the community and advance scientific and clinical research.

There are several ways to bequeath money to the Prader-Willi Syndrome Association:

- We will gladly accept funds and/or securities that can be used for general purposes, as was the instance in our most recent estate gift.
- A will could specify a particular project(s) (e.g., YAP, Research); program(s) (e.g., Parent Mentoring); or staff position (e.g., Crisis Counselor).
- A bequest could also be channeled to the Association's Endowment Fund.

The Endowment Fund is a permanent source of financing invested conservatively to increase the value of the fund. The income from dividends and interest is used by the Association for important programs and projects. Because the principal is designed not to be used, it provides a necessary ingredient in securing our financial future.

A bequest may be either:

- Specific: An amount of cash, a designated asset (stock and/or bond), or an account (IRA, Retirement Plan, brokerage and/or bank account);
- Residuary: A gift made after all other specific bequests, taxes, expanses and debts have been satisfied;
- Contingent: A gift completed only after other conditions are met. For example, a married couple may want to leave money to PWSA (USA) only after the death of a primary beneficiary (wife, child, grandchild, etc.);
- Memorial: A gift given in the name of the decedent, serving as a constant reminder of their support of our cause.

While the Federal estate tax was reduced again in 2005, many states continue to tax estates at old rates. Bequests of cash, securities and other assets to PWSA (USA) entitle your estate to a charitable deduction that can reduce or eliminate estate tax liability. PWSA (USA) is a 501(c)3 IRS-qualified charity, and copies of our tax-exempt letter are available upon request.

**Using estate gifts can help us seek brighter futures for both children and adults with PWS.**

For those interested in including the Association in their will or in other elements of their financial plan,

please feel free to contact Steve Dudrow or Janalee Heinemann at (800) 926-4797 and we will be happy to work with you and your legal and financial professionals. Of course, all inquiries will be held in the strictest confidence. **NOTE: The information in this article is not intended to serve as legal or tax advice.**

*PWSA (USA) Board Member Stephen Leightman is the grandfather of Josilyn Levine, almost 3, who has PWS.*

## Praise for PWSA (USA)...

We recently received a gift from a family member for our son's special needs trust. After hearing about your operating budget deficit, I felt we needed to contribute some of that gift directly to you, to support the work you do. I know my son would not be doing as well as he is without PWSA. Every time I meet with new teachers, doctors, therapists, I am armed with info and brochures put out by PWSA to help them better understand my son and his needs. I count on PWSA to have seed money for research projects to ensure a better future. And, I have learned so much at conferences. Thank you for all you do to make things better for our family members with PWS!



## Fund-raising

# Fund-raising With A Flair for Creativity!

By Lota Mitchell, Associate Editor

Opportunities to raise money to benefit PWSA (USA) are limited only by one's creativity, as recent efforts by dedicated members have shown. Take **Mykenna "Mickey" Phernetton's** story.

Her father **Patrick** writes that he and wife **Lisa** were devastated when they learned at two weeks that she had PWS.

They researched, planned, coped, and prayed. In 2003 Patrick asked a friend who played in a band to do a charity concert; that raised \$700.

Then last year he says, he "had the fortune to meet Ronnie Paul Kingery of the country music group Hometown News," a national band that was nominated for "Country Music Duo of the Year" at the ACM awards. Patrick was stunned when they agreed not only "to come to Evansville, Indiana, to play a charity concert for a little girl they had never even met before... but have made it a point to learn about PWS and care about our kids." The concert in October 2004 raised more than \$3,000 in one night.

"The highlight of the night for us as parents," says Patrick, "came when Ronnie Paul stopped between songs, blew Mickey a kiss from the stage and told her he loved her. She smiled from ear to ear and blew him a kiss back. Since then we have traveled to other cities to see Hometown News in concert and each time Ronnie Kingery and Scott Whitehead have made it a point to say 'Hi' to Mickey and blow kisses to her. She even gets to hang out with them while [they are] signing autographs. She is very quick to point out that SHE is their best friend!" Mickey feels so special!

Part of the success of the concert was due to the tons of media coverage they got — part luck and part diligence on their part, Patrick says. He contacted a local television reporter that they knew, told her about the concert, asked for a story about Mickey and PWS, and help to promote the concert. It happened. They called a second television station, which also agreed to help. Before the week was over, Mickey's story and the concert was on the news at least once a night for about 7 days straight — plus a local country radio station had them on three times that week, plus several public service announcements, plus a story in the local newspaper. Wow!

Then how about **Carmen and Joe Donovan** of Montezuma, Iowa, who celebrated their son Riley's third birthday by starting Walk-a-Mile For Riley. This meant that for every \$5 donated to PWSA(USA) on behalf of Riley, diagnosed with PWS as a newborn, either Joe or Carmen would walk one mile. Their goal was to raise \$5,000 and walk 1,000 miles by Dec. 31. They have now raised in

excess of \$6,000 for research and awareness (no report on how many pair of shoes have worn out).

And there's **Christie Bevaqua**, from Tinton Falls, New Jersey, who put on a dinner dance which raised more than \$11,000 for PWS research. Fabulous! She and husband Kevin are the parents of 2 ½ year old Jack, who has PWS.

**Awareness Week 2005** is coming up May 1-7. This year wrist bands will be available that can be purchased and worn not only during Awareness Week, but any time of the year. Those who have the wristbands are asked to be sure to wear them especially during Awareness Week. Many chapter, affiliates, and individuals choose to plan events in conjunction with Awareness Week, such as Walk-a-thons and bowl-a thons. If you would like help in planning an event, or if you are planning a project during Awareness

**Hometown News agreed not only to come to Evansville, Indiana, to play a charity concert for a little girl they had never even met before... but have made it a point to learn about PWS and care about our kids.**

Week, please let us know about it.

Contact Jodi O'Sullivan at the national office or e-mail her

at [comdev@pwsausa-org](mailto:comdev@pwsausa-org). Your help will ensure a week of success!

In the words of Patrick Phernetton, "Alone we are just a drop of rain in the bucket. Together we can fill the bucket!"

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## Conference - continued from page 1

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rate for Saturday night so families can enjoy Saturday at their favorite theme park and take advantage of cheaper air fares for a Saturday night stay-over rate.

To avoid any overcharge or problems with registration, please make your room reservations by contacting Globetrotter Travel at 800-322-7032 (press 2) or via e-mail to [pwsa-usa@globetrottermgmt.com](mailto:pwsa-usa@globetrottermgmt.com). You can also make hotel reservations online by contacting [www.globetrottermgmt.com/pwsa-usa](http://www.globetrottermgmt.com/pwsa-usa).

All our volunteer program directors have past experience with conference, and the Sheraton World Resort has committed to a significant increase in meeting space both for the parent programs and YAP, so this upcoming conference is projected to be bigger and better than ever! Watch our web site and the next Gathered View for more details on programming.

## Special Needs Tax Guide Available Online

The Schwab Learning site has a tax guide for parents of children with special needs that outlines some of the benefits that their children with disabilities (including learning disabilities) may be eligible for. <http://www.schwablearning.org/articles.asp?r=773>

## *Contributions In Memory Of*

Jeremy Girard  
 Roger C. Walker  
 John E. Miller  
 Deborah Meyer  
 Employees @ MCO ATCT  
 Samuel & Grace Appleby  
 Robert & Wauneta Lehman  
 Rodney & Sandra Taylor  
 Michelle & Tommy Torbert  
 Sandra Stone  
 Patricia Robertson  
 Maria J. Veglucci  
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 Paul & Elizabeth Wagner  
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**Catherine Forlenzo**  
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**Elinor S. Hearn**  
 Tim & Carol Hearn  
**Clyde Mays**  
 Hope Mays  
 Pamela Eisen

## *PWS in the News*

### **BBC Documentary**

BBC (British Broadcasting) produced an excellent 1-hour documentary on Prader Willi syndrome called "It is not my fault I'm fat!" Executive Director Janalee Heinemann worked with the BBC production staff, and PWSA (USA) and PWS (UK) are credited at the end of the documentary.

The show is airing on the Discovery Channel in the U.S. in March, and will be aired at the PWSA (USA) national conference this summer.

BBC followed three families for months: two from the UK and one from the U.S. A thank you goes to our family who agreed to be featured as their daughter went through The Children's Institute. The documentary showed before, during and after placement. The UK families were a young man who finally went into permanent placement, and one who kept his rights to freedom and was close to dying from his obesity. It shows the harsh realities of PWS, yet is sensitive to young people with PWS and their tragic disability.

### **Videoconference on PWS**

In January Dr. Linda Gourash presented a 2-hour videoconference on "Prader-Willi Syndrome: The Behavioral Challenge" to 122 registered participants. Sponsored by the Department of Psychiatry of the University of Pittsburgh School of Medicine, the video-conference was broadcast to 14 sites at mental health hospitals and clinics in Western Pennsylvania as part of their CME (continuing medical education) series for physicians and other mental health professionals. Dr. Gourash is a member of the PWSA (USA) Clinical Advisory Board.

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