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Our 31st Year of Publication

The Gathered View

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

Jason Fetsko, Ohio

In this issue

The Jellybean Conspiracy

High School Play Teaches Kindness, Spotlights PWS

By Jane Phelan, Editor

Consider the wonderful diversity of jellybeans. Sophomore Emily Weingart, 15, who has PWS, was featured in the Hiawatha, Kansas high school production of "The Jellybean Conspiracy" in November. The play uses drama to create communities of caring in high schools. It's a heart-warming story of courage, kindness and compassion, and demonstrates thoughtful inclusion.

Emily Weingart (2nd from right) on stage with cast members of "The Jellybean Conspiracy"

Act One is an anthology of poems, songs, stories, monologues and scenes that depict society's response to people with disabilities and offer glimpses of a kinder, more tolerant and inclusive world. Act Two presents a teenage girl's awakening as she comes to terms with the reality of her sister's disabilities and the gifts she offers to the world.

Emily's sisters — Sara, Annie and Elizabeth — also participated. "It went so well, and everybody received so many positive comments," said their mother, Nancy Weingart. "We had kids that never had been in a play before (my oldest included), and football players and just all kinds of kids that just had a positive experience from it," she said. Proceeds from the production benefited PWSA (USA).

"The community was just in awe over the play. It was such a positive experience for everyone and we are so lucky that our girls were all involved; it is something they will never forget for the rest of their lives," Nancy Weingart reported.

Jellybean was founded in 2001 by Dr. Howard Martin, a professor of theatre at the University of Missouri Kansas City, who has three siblings with severe multiple disabilities.

"Look at a jar of jellybeans and think about the universe these colorful candies live in," writes Dr. Martin. "It's a universe where every bean has its own special place and where each at some time hears the words: 'This jellybean is just right.' Now imagine a human community as a jar of jellybeans. Each person is recognized as having a unique and irreplaceable contribution to make and each is able to hear the words: 'This person is just right.' "

Following the weekend shows were two days of workshops for students that focused on themes from the play, such as diversity, tolerance and respect.

"We call it a 'conspiracy' because it brings people together to pass on a secret," Dr. Martin writes. "In essence, the Jellybean Secret is this: everyone's life is important. Surely that's a secret worth passing on. And there's no better way to do so than through the theatre."

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Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6 . Sarasota, Florida 34242
1-800-926-4797 9 a.m. to 7 p.m. Eastern Time
Local telephone: 941-312-0400 . Fax 941-312-0142
e-mail: national@pwsausa.org . web site: *www.pwsausa.org*

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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.

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!
User Name: pwsamember Password this issue: tiger06
Note: If you have difficulty logging in to the site, you may be using a browser that prevents you from entering authenticated websites. Try minimizing your program (e.g. AOL) and clicking on Internet Explorer or Netscape. Then type in the URL: http://ww.pwsausa.org/only

Deadlines 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

PWSA (USA) Awards Two Major Research Grants

By David M. Agarwal, M.D.

In its most recent round of research grant evaluations, our PWSA (USA) Governing Board and Scientific Advisory Board (SAB) agreed to fund two new PWS research studies, granting $104,758 to Dr. William J. Klish at the Baylor College of Medicine in Texas to study the "Impact of dietary content upon gastrointestinal motility in individuals with PWS" and $49,248 to Dr. Teresa M. Reyes at the Scripps Research Institute in Florida to study "The expression and regulation of necdin in the mouse central nervous system: relation to hyperphagia." These are both two-year grants that represent PWSA (USA)'s ongoing commitment to clinical and basic research to understand Prader-Willi syndrome and address medical questions raised by our members and families.

Dr. Klish's research: Meals that contain large amounts of carbohydrates and can quickly raise blood sugar levels (high glycemic index meals) are known to increase appetite. On the other hand, meals that contain large amounts of fats are known to slow down how quickly the stomach empties into the intestine. This slows the breakdown of carbohydrates and absorption of sugars and keeps blood sugar levels relatively lower. In PWS, this delayed gastric empting may relate to gastroparesis, in which the stomach stretches with food that accumulates because of ineffective stomach contractions (when severe, this can lead to stomach rupture).

Dr. Klish's team, headed by Dr. Ann O. Scheimann, will study how quickly meals with varying fat and carbohydrate content exit the stomachs of people with PWS, the gut hormone responses to meal content and the relationship of the type of meal to how full that person feels after eating. In addition, blood tests before and after each meal will help check the relationship of ghrelin and other gastrointestinal peptides to stomach emptying. This grant will further our understanding of the signals that make a person with PWS feel hungry or full and may alert parents and medical providers to a dietary component to gastroparesis, and potentially, to gastric perforation.

Dr. Reyes' research: One of the proteins made by chromosome 15 genes that are disrupted in PWS is called necdin. Necdin is found in the brain (particularly in the hypothalamus) and is needed for normal development and interconnection of brain cells. Because hypothalamic dysfunction may change the secretion of neurotransmitters that affect appetite and because small hypothalamii and increased appetite are hallmarks of PWS, researchers suspect a necdin deficiency may cause the insatiable hunger associated with PWS. Dr. Reyes and her team will examine how necdin is expressed in brain cells and if expression relates to appetite. In mice, she will examine how to identify brain cells that express necdin, if necdin levels are different in varying models of over-eating, eating schedules, and chemically-stimulated hunger, and if artificially deleting the necdin gene leads to hungrier mice. Dr. Reyes will also draw upon funding she has already obtained from her K-01 grant from the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health.

In other research news: a November 2005 article called "Obestatin, a peptide encoded by the ghrelin gene, opposes ghrelin's effects on food intake" was published in *Science* by Jian V. Zhang at Stanford University. We know that in humans, ghrelin is a peptide hormone produced by the gut that stimulates food intake and weight gain, and that levels of ghrelin in adults with PWS are higher than levels in obese people without PWS. This research team made a second peptide from the gene that codes for human ghrelin and named it obestatin. When given to rats, synthetic obestatin did the opposite of ghrelin: it decreased food intake, suppressed stomach emptying, and decreased weight gain. However, the rat's obestatin levels didn't go up after meals, so we're not sure if obestatin can actually "tell" rats they are full and make them stop eating. We also don't yet know if humans make obestatin, nor if human obestatin can suppress appetite. Some of our PWSA (USA) researchers report they will be following up with this interesting potential.

Pittsburgh Partnership, PWSA (USA) & Friedman Foundation Educate Psychiatrists

In October, 2005 Janice Forster, M.D. and Linda Gourash, M.D. (The Pittsburgh Partnership), together with Glenn Berall, M.D., presented a well-received Clinical Perspective, "Lessons from PWS: Integrating Weight and Behavior Management," at the joint meeting of the American Academy of Child & Adolescent Psychiatry (AACAP) and the Canadian Academy of Child & Adolescent Psychiatry in Toronto, Canada.

At the same meeting, Drs. Forster and Gourash presented a workshop, "Neuropsychiatric Phenomenology and Management in PWS." PWSA (USA) printed the new *PWS Primer for Psychiatrists* and distributed packets of PWS information (including the DVD *Food Behavior & Beyond)* to workshop attendees. Along with the presentations, PWSA (USA) sponsored a booth, where 400 copies of the new PWS Primer were distributed. David Wyatt and Ken Smith worked very hard throughout the conference to provide information about PWS to psychiatrists who stopped by the booth. Dr. Forster reported: "We definitely succeeded in our mission to get appropriate clinical information about PWS out there in the North American psychiatric community."

As a result of this meeting, PWSA (USA) now has contact information for psychiatrists from the U.S. and Canada who are currently seeing individuals with PWS and those who are willing to accept referrals. To our knowledge this is the first time PWS has been discussed extensively at

Psychiatrists continued on page 15

28th PWSA (USA) Conference
July 19-21, 2006 Holiday Inn, Grand Island, NY

A JOINT EFFORT WITH NEW YORK STATE CHAPTER, PRADER-WILLI ALLIANCE OF NEW YORK, INC.

Scientific Day, July 19th – Intent to submit abstracts due January 31, 2006


Dr. Moris Angulo

Conference Chairperson is Moris Angulo, M.D., director of human genetics, associate director of pediatric endocrinology/metabolism at Winthrop University Hospital, who serves on the PWSA (USA) Clinical Advisory Board. A renowned PWS endocrinologist and geneticist with an office in Mineola, New York, Dr. Angulo is a pioneer in the use of Growth Hormone for the treatment of PWS. He has written and lectured all over the world on the use of Growth Hormone in the treatment of PWS.

Speakers invited to present are:

Urs Eiholzer, M.D. has led the "Institute Growth Puberty Adolescence" since 1992 and maintains a private practice in Zurich and Lausanne. His clinical research deals with PWS growth-related questions, and he has authored numerous scientific publications and several books, including *Prader-Willi Syndrome: Coping with the Disease – Living with Those Involved.*

David E. Cummings, M.D. is an associate professor of medicine in the Division of Metabolism, Endocrinology and Nutrition at the University of Washington and the V.A. Puget Sound Health Care System. He studies hormonal and neurochemical pathways that regulate appetite and body weight, including the physiologic functions of ghrelin, a recently discovered, appetite-stimulating hormone.

Elisabeth M. Dykens, Ph.D. is professor of psychology and human development, associate director of the Vanderbilt Kennedy Center for Research on Human Development, and director of Vanderbilt Kennedy University Center of Excellence on Developmental Disabilities. Her research examines behavioral phenotypes of genetic syndromes associated with developmental disabilities, primarily Prader-Willi, Williams, and Down syndromes.

Providers Day, July 19th

We're developing educational and supportive topics for providers. More information will be available on the website and in the registration packet available after April 1, 2006.

General Conference, July 20th – 21st

We're planning two days of education and fun for the whole family! Program tracks for attendees will be: Infant to Age Five, School Age, Transition and Adults. Details will be available in the next Gathered View and in the registration packet available after April 1st. Keep checking the PWSA (USA) website for the latest details regarding conference: www.pwsausa.org

Globetrotter Travel has special PWSA (USA) discounts for accommodations, rental cars and airfare. Fly into Buffalo Niagara Airport (BUF). The hotel is only 20 miles from the airport and 15 miles to Niagara Falls. The hotel rate is $99/night. To make reservations, use Globetrotter Travel. Call 1-800-322-7032 (press #2); e-mail pwsa-usa@globetrottermgmt.com or see their web site http://www.globetrottermgmt.com/pwsa-usa/

Plan NOW for 2006 Conference grant requests

Start to look at alternative, local grant sources. Have your request in writing, be prepared before you call. Do not wait- many funds get used up early in the year.

- State Developmental Disability Council – 1-800-695-0285
- NICHCY or check their web site www.nichcy.org
- Check for funding through your local church
- The ARC (disability related funding)
- Parent-to-Parent (disability related funding)

And then…PWSA(USA) Grants. Please use these criteria to prepare your grant request to PWSA (USA): Names of family members to attend (maximum 4 people, please); children's ages; address, e-mail, and phone numbers. Reason you want to atttend, what you hope to achieve and how you'll share information. Explain special financial and/or emotional needs of your family. Specify dollar amount needed and its purpose, i.e. registration, lodging, travel, etc. How much can you put toward the cost? What grants have you received before (national or local conferences)?

All grant recipients will be required to be or become members of PWSA (USA). If the membership cost is a problem, a Scholarship membership can be requested. Grant funds apply ***only*** to those registered for the conference programs. Grant funds may not be used for extra nights' lodging, food, etc.

So that we can assist more families, grants may not always include air fare. All reservations will be made through our travel group. **Submission Deadline is March 31, 2006 for PWSA (USA) grant applications.**

- E-mail grant requests to: national@pwsausa.org
- Fax to: 941-312-0142
- Mail to: Prader-Willi Syndrome Association (USA)
  5700 Midnight Pass Rd. Ste. 6
  Sarasota, FL 34242
  Attn: Grant Committee

Get the latest info at www.pwsausa.org

Medical Alert

Food Security for PWS

By Janice L. Forster, M.D. and Linda M. Gourash, M.D., Pittsburgh Partnership

Have a Plan: A person who needs food security should never enter a "food situation" without knowing what the plan is for maintaining his or her dietary needs.

Food insecurity contributes to over-eating, poor nutrition and obesity. Food security is defined as the ready availability of nutritionally adequate and safe foods with an assured ability to acquire acceptable foods in socially acceptable ways. The principles of food security are:

- √ ***No doubt*** when meals will occur and what foods will be served.
- √ ***No hope*** of getting anything different from what is planned.
- √ ***No disappointment*** related to false expectations.

Here are some ways to achieve food security:

1) Secure food accessibility across *all* settings by:
   a) Controlled access to:
      i) Refrigerator, freezer and pantry
      ii) Vending machines
      iii) Money
   b) Avoiding any spontaneity related to food
   c) No snacks on demand
   d) No food left out
   e) No "free" foods or beverages
   f) Absolute portion control
   g) Pre-packaged condiments

2) Supervise food exposure:
   a) At stores
   b) During food preparation and mealtime
   c) During special occasions (birthday parties, seasonal celebrations, etc.)
   d) When dining out in the community…
      i) Access menus from restaurants in advance and decide what will be ordered.
      ii) In general, buffets are understood to be "off limits" Or, if unavoidable, it is understood that the plate will be prepared by someone else.

3) Post the schedule for mealtimes and snacks.

4) Post the schedule and the menus for meals and snacks.

5) If necessary, because of raised expectations or anxiety, avoid places and social situations associated with excess food

 Drs. Forster and Gourash serve on the PWSA (USA) Clinical Advisory Board.

Some individuals need all of these measures; others only some

Another Holiday GI Death

A 28-year-old young woman died suddenly on November 26, 2005. She was at a good weight and had been in placement for several years. She was home for Thanksgiving and "ate a lot" according to mom. Friday she was vomiting profusely. On Saturday, she had diarrhea, but said she was hungry. She passed out and mom called an ambulance. They were unable to revive her. No autopsy. Fluid found in her lungs, so ruled her death as asphyxiation. Our physicians believe the primary cause of death was related to the GI necrosis and/or perforation deaths we have been seeing, particularly over the holidays.

We are taking several actions to further alert parents and providers. **WE NEED YOUR HELP, YOU CAN SAVE A LIFE**! We must get a warning to all providers and see that they get a very clear warning to all parents who have adult children in placement. With the help of Dr. Barb Whitman, we wrote sample letters, and PWSA (USA) sent them to 368 providers for them to use when they send a person with PWS for a home visit. For a copy, go to www.pwsausa.org or call the National Office at 1-800-926-4797.

The classic situation is that the person with PWS is slim due to being in a controlled environment, but when he/she goes home for a visit (especially during holidays) everyone gets lax, thinking a few pounds won't kill them. Well, a few pounds might not kill them, but an overeating binge might! **HELP US SPREAD THE WORD.**

A Parent Comments on Food 'Freedom'

It is difficult when a person with PWS comes home for a visit and is tempted by all the "food freedom" that we enjoy as "normal" people. My interactions with my daughter are just great prior to going out for lunch or going to a relative's home for a holiday, but all heck breaks loose when the meal is over and she knows that no more is coming her way. One day a close friend asked me to bring Kathleen to their home for Christmas, saying that I could just relax and let her eat what she wanted. I just looked at them and said "NOT."

Four years ago Kathy was admitted to St. Johns Hospital in St. Louis due to "aspiration pneumonia." I know now that it was a result of my letting her eat more than usual (we were at the lunch following her father's burial) and I was more lax in my diligence. She almost died; the ICU physician said that he doubted she would recover, but thankfully she did. It was a very scary time. My point is: I did not let her binge, she ate more than usual, probably like "normal" people, but she has been slender for almost 10 years now (if not more) and this recent death has been an unfortunate reminder of what she cannot do. — ***Regina Hollrah, St. Charles, Missouri***

President's View

Understanding Is How You Can Help

Carolyn Loker

Dear Parents and Caregivers of children/adults with PWS,

I have written the following letter for you to give, if you wish, to your family members and friends so they may have a better understanding of the help that we as parents need to support us and our precious children:

For those of you who are helping and supporting your friend or family member who has a child with Prader-Willi syndrome, we thank you from the depths of our hearts.

For those who may not understand our need for your support, let me try to explain. I never really completely understood the magnitude of an old African proverb stating "It takes a village to raise a child" until I had a child with Prader-Willi syndrome. Our "village" includes an array of doctors, therapists, school personnel, PWSA (USA), etc. We need everyone to be in our PWS village if we are to make a difference in the lives of our beloved children. We need support and understanding, a shoulder to cry on, a quiet walk, or a promise of hope.

We understand that it's sometimes hard to know what to say or do, that maybe you might feel a bit awkward or afraid that you might say too much or not enough. You might even be going through your own grief for our precious child and this child's parent.

Let us hear your voice, let us see your tears, let us help you understand the world we live in with our children. Once we break through those barriers, then we can begin to build our village with you inside helping us, helping our child. We know you cannot ever completely understand because you are not walking in our shoes, but just walk beside us and hold our hand so that we will not falter or fall.

Here are some words you could say:

- "I don't know what to say, but I want you to know I'm here to help."
- "I don't understand what you're feeling because I've never dealt with this, so please tell me when you feel I'm being insensitive or I don't understand.
- "I understand your time is limited because of the care, so tell me if I can be a caregiver so you can have alone time, or let me grocery shop for you."

Here are some things you could do:

- Ask the parents if they would like you to have a family education get-together, inviting friends and family members over without little kids. This would give you time to talk with them, ask questions and let them know you are there to help.
- Send cards, and keep calling even if the parent does not respond. Often their lives are so busy because of their child's needs. Let them know you care without any strings attached.
- Be understanding of the PWS family rules. They might seem too strict to you — or not strict enough — but these rules are in place to allow the child to be healthy and to try to alleviate behavior issues.
- Please don't leave food out if a family with a child who has PWS is visiting, including the holidays.
- Volunteer to be the watch person in half-hour or hour shifts to ensure the child doesn't get unauthorized food. When your shift is over, clearly identify the next watch person.
- If you can't/won't modify your gathering, tell the parents and they'll know not to bring their child to your house.
- If the child has a behavior issue, let the parent handle it.

We need support and understanding, a shoulder to cry on, a quiet walk, or a promise of hope.

I'm often asked whether I would take this syndrome away from my child if I could. Absolutely, without a doubt! Would I be giving up her sweetness and innocence? Maybe, but I would also be taking away the hunger that haunts my precious child every minute of every day. We know that we cannot banish this syndrome, but with the help of friends and family members we can begin to feel the promise of hope — the hope that will help cure our children's hunger.

Many parents just live day to day, trying to cope with caring for their child's needs, and do not have time to be involved with helping to find the cure for the hunger. If you are wondering what else you can do, please talk with the parents of the child and tell them you are there for them. PWSA (USA) has many aunts, uncles and grandparents who are helping. Some serve on our board of directors, some are officers, and some have successful fundraisers.

Also, please consider calling our PWSA (USA) office for information, becoming a member, offering support or possibly a monetary "promise of hope" gift. If you are interested in obtaining information on doing a fundraiser, we can help you. These are more very welcome ways to be a part of our village. Many thanks.

Hugs, Carolyn Loker, mom to precious Anna
Prader-Willi Syndrome Association (USA)
1-800-926-4797 * www.pwsausa.org

Executive Director's View

Which Is More Important? Your Child's IQ or SA?

Janalee Heinemann

It is exciting to see the new generation of children with PWS who have early diagnoses, early intervention therapies, and are on growth hormone (GH). In general, they are much slimmer and more active than the generation before them. Thanks to GH and early therapies, they have been more intellectually stimulated partially because they have the energy to be more interactive. We wonder if, when they get older, we'll find that on average they will function higher intellectually.

Current research has shown that children not allowed to become very obese early in life may have higher IQs. Our CAB chairperson, Dr. Dan Driscoll, has compared his patients with PWS and non-PWS children who had early morbid obesity to their slim siblings. They controlled for family differences by comparing them to their sibs who share the same environment and similar genes but who are not obese, and the findings were: "*Thus, individuals with early-onset morbid obesity have significantly lower cognitive function and more behavioral problems than controls with no history of childhood obesity. Therefore, childhood obesity alone may result in compromise of cognitive ability and achievement, adding to the public health concern surrounding the epidemic of obesity in childhood.*"

So the good news is that you may be able to influence your child's IQ. That said, seeing so much pressure on parents to give all they have to increase their child's chances in this world, I have to ask myself, What will really enhance the quality of the life of the child with PWS the most? What will enhance the quality of family functioning?"

No matter how many hoops a parent jumps through, there remain large ranges in IQ functioning among our children with PWS — and much continues to be the luck of the draw of genetics. Some of the most devoted parents I know still have children with lower IQs. I've also witnessed some of our higher functioning individuals having the most problematic behavior. So where should our focus lie?

Personally, I think our primary focus should be on our children's social adaptation (SA). How will your child get along in society? One of the best examples of a high SA is Daniele, the 29-year-old son of our past international president, Giorgio Fornasier. Giorgio and his wife Maritzia, who live in Italy, do not know exactly what Daniel's IQ score is and are not concerned enough to find out; they think it is around 75-85. Daniele didn't have some of the advantages of the current generation and was never on GH. What Giorgio and Maritzia have focused on are Daniele's social skills.

On our recent vacation to Italy with our daughter Tracy and her husband Tony, Al and I spent 10 days traveling with the Fornasiers. Although I've spent time with Daniele before, 10 full days with an adult with PWS who is not your own child is a true test! He could not have been more charming.

Daniele would come each day to greet us with a cheery "Good Morning!" and a kiss on each cheek. He would then greet the hotel staff prior to escorting us to the van, where he would hold the door open and see that each of us securely fastened our seat belts. Each place we went, Daniele would greet people and see in all ways that we were well cared for and introduced.

On several occasions we had the opportunity to hear Giorgio sing (one of his many talents is as an opera singer), and on two occasions it was for a mass. Daniele was an altar server at both services and was very professional in his role. During one of the events, he was the key altar server for the bishop during a festival. Daniele escorted the bishop arm-in-arm to the church and seemed to know exactly when to lift the microphone to the bishop's mouth, etc. The only slight glitch was during the bishop's sermon. (If you know how easily our "kids" with PWS fall asleep, you will appreciate this.) As the bishop talked on and on, we heard a loud CLUNK on the floor of the altar. Daniele, who was quietly sitting during the sermon, had fallen asleep and dropped the portable microphone, which was still turned on. This woke us ALL up!

Besides being cheerful, very social and polite, Daniele is also intuitively very sensitive. He had previously met our grandson Adam, Tracy and Tony's son, who died last year. While many people don't know what to say or do, Daniele would openly tell people (in Italian) about Adam, pressing his fingers first to his lips, then on the pin that Tracy always wears, which is a framed picture of Adam.

I have observed this sensitivity in other children and adults with PWS. Last year during our Christmas trip to Tracy and Tony's, I wondered how we would all handle the first Christmas without Adam, Tracy's only child. Our own 32-year-old son Matt, who has PWS, probably was the most appropriate and sensitive of all. He took extra care in picking out their gifts; he seemed to sense when Tracy or Tony were sad and would just give them a big hug. When Matt was leaving and hugging Tony good-by, he whispered something to him. Tony told me later what Matt said: that Tony reminded him of Adam.

So, what is the IQ of Daniele and Matt? Does it really matter? They have grown up to be more kind, sensitive and polite than most young people their age. Perhaps their SA is what matters most of all.

Fundraising From the Home Front

With Help Like This, We Can Do So Much For Our Kids

The energy and creativity of families raising money and awareness for Prader-Willi syndrome are truly awesome! Here are some reports from around the country.

Golf Events

Madison Hurdle, 3, who has PWS

With an assist from **Darrin Kerbs and Kevin Mullen, Clint and Karla Hurdle** of Colorado raised more than $57,000 for PWS research at the **2nd Annual Golf Fore Prader-Willi Syndrome Association (USA) Charity Tournament in Honor of Madison Hurdle**. "As we started to organize the event, I got to know more about Prader-Willi and of course I was able to get to know Karla better and develop more of a personal connection and compassion for what they go through every day of their life in raising a child that has Prader-Willi," Kevin Mullen reported. "That motivated me to not just survive the organizational process, but truly make it a success." Kevin recommends starting early to plan your golf event. "There are sooo many charity events for people to choose from (especially golf tournaments) every year. It is critical to get on the calendar for participants early in the year so they can plan and commit to your event. …We were unbelievably successful with only two months planning the event. I can only imagine what we will do with more time this next year." Sounds like a winner to us!

Kim Belisle and Ed Kennedy worked with **Terry Sourbeer** on the **2nd Annual Dulevich-Napier Charity Golf Tournament** in Florida and brought in more than $19,000 for PWSA (USA). "It is always special how the community comes together during functions like these," Kim Belisle wrote, adding "If anybody wants to do a fund-raiser for PWSA (USA), I think it is a great organization."

Nathan's Tag Sale

Here's a great twist to the traditional tag sale. This summer **Michael and Gretchen Bennett** of Plantsville, Connecticut, parents of 1-year-old-**Nathan**, who has PWS, raised both PWS awareness and more than $400. Gretchen's mother, **Deborah Carpenter,** who belongs to freecycle.org, a grassroots movement to promote waste reduction, came up with the idea. She asked those in this group to donate items for use in the sale. Mike and Gretchen sought donated items, advertised around town and set up the tag sale, where everything was *free!* They asked people to consider making a donation to PWSA (USA) and handed out PWS pamphlets for awareness. One person gave $5 for a cassette tape. They also sold drinks and snacks.

In a pleasant surprise, **Jan Colturi**, whose 4-year-old grandson, **Carter Shingleton**, has PWS, volunteered to help. She and her husband **Troy** and **Deborah's husband Al** all hung out in the heat to help sell stuff, too.

On-going Tupperware Party

Yolanda Orneles has already netted $140 in Tupperware sales, and pledges to give **100% of the proceeds of ALL her online sales to PWSA (USA)**. "There is no time limit," she stated. "I feel I'm working for a company that helps people in need and I had the opportunity to do it. I'm giving all this effort in honor of all the children and parents of PWSA."

Yolanda was introduced to PWSA (USA) through **Rosa Combs**, of Freeport, New York, whose daughter, **Stefanie**, 14, has PWS. "I salute all of you for the job you are doing for your children and thank you for giving me the opportunity to work with some of you who e-mail me. I really wish I could give more," Yolanda wrote.

You can make online Tupperware purchases and throw an online Tupperware party at Yolanda's web site knowing that 100% of your purchase will benefit our loved ones with PWS. For more information, visit www.my.tupperware.com/yornelas or call Yolanda at 347-203-4546 or 718-659-7550.

Knowing is not enough; we must apply. Willing is not enough; we must do.

— Johann von Goethe

Lose-A-Thon

If you've wanted to lose weight, but have just needed a reason and motivation, PWSA (USA) has the answer. Ask friends, family and anyone else to support your weight loss efforts with a financial donation to PWSA (USA). Sign up by the end of January and pledge to meet your goal by May 1, 2006, in time for Awareness Week. We've made it simple for you to do with a sample letter and donation form already drafted and available to you online at www.pwsausa.org or by calling our office.

You may also sign up on our web site to create your own online Lose-A-Thon Web page where your donors can make their contributions. Tackle this challenge with a friend and other Lose-A-Thon participants from around the country and gain strength and encouragement from each other. Reach for the coveted title of "Incredible Loser" and know that in our eyes, you're a winner!

— Jodi O'Sullivan, Director of Community Development

Awareness Week

It's not too early to start thinking about PWS Awareness Week, April 30-May 6, 2006. Plan a PWS Awareness Week Walk with the official PWSA (USA) walk theme, "You'll Never Walk Alone." Start now and secure your location, call or e-mail our office to let us know about any type of event you want to do! We'll send a PWSA (USA) Walk Event Planning Guide and other event tools to assist you. Visit the Awareness Week section on our web site for LOTS of other ideas and helpful tools that you can use to spread awareness of PWS.

Let's get something going in every state!

Making A Pilgrimage for Megan

Last fall Lauren Deines visited Spain and made the Camino Santiago Pilgrimage to honor her daughter Megan, who has PWS, and to raise funds to benefit PWSA (USA). Lauren walked more than 156 miles in 14 days and received her "compostella" certificate of completion on October 3 in Santiago during the solar eclipse.

"This is one of the most rewarding things I have ever done," Lauren wrote. "I feel that my life may be measured as BC (Before the Camino) and AD (After De Compostello). The Camino De Compostello is the name of the Pilgrimage of St James in Spain. It sure changes your life to walk a sacred path with hundreds of pilgrims from all over the world.

"The people you meet are incredible: other pilgrims, and all the people who have dedicated their lives to assisting pilgrims. Everywhere I went everyone told their stories of why they were walking. Taking time from their lives to consider their spiritual selves and to heal from life's tragedies and losses. You carry a stone from home to lay on the top of the mountain of the iron cross to represent your burdens and regrets that you leave on the trail. I told all about walking for myself and my daughter Megan, age 6, who has PWS, and was accepted and encouraged by all."

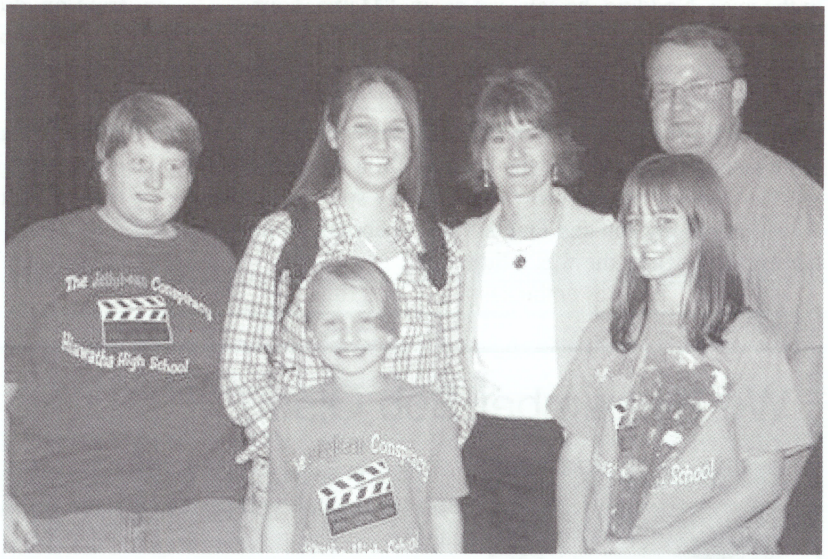
On the first day that Lauren was in Madrid, before she made the pilgrimage, she and her sister went to the world-famous Prado museum. Hanging there was a painting from the 17th century of Eugenia Martinez Vallejo, daughter of Felipe II of Spain, who is believed to have had PWS. Lauren told her sister she suspected Eugenia had PWS even before she learned that historians suspected it too. Lauren was really touched, because the painting was done when Eugenia was 6 years old, the same age as Lauren's daughter, Megan. She and her sister were crying as they stood before this painting. It was a very spiritual experience for Lauren.

Before she left for Spain, Lauren had a photo of her daughter Megan dressed as a princess applied to a T shirt that she could wear during her pilgrimage. Lauren wrote that she also carried a copy of painting of Eugenia Martinez Vallejo with her. "I felt her history deeply, knowing today what light we shed on making PWS understood like never before," Lauren stated.

*Editor's Note: Eugenia Martinez Vallejo was the subject of a painting by Juan Carreno de Miranda, a painter to the Spanish Court, at the order of King Charles II in 1680. She was a 6 year old weighing 120 lbs with excessive central obesity, a small triangular mouth, and small hands and feet. Sadly, the painting was titled "La Monstrua." You can view the painting at this web site:*http://www.oceansbridge.com/art/customer/product.php?productid=28366

Jellybeans - *continued from page 1*

Since inception the show has been performed 70 times at 18 schools with an average attendance of 200 per show. It has directly engaged the abilities of more than 85 young persons with disabilities, including 18 who have played the lead role in the show. For information about the Jellybean Conspiracy program, visit the web site, http://www.jellybeanconspiracy.org.



The Weingart family L-R: (front): Annie and Sara (back): Emily, Elizabeth, Nancy and John

About Emily Weingart

Emily was 7 pounds, 2 ounces when she was born March 27, 1990 in Atchison, Kansas, the daughter of John and Nancy Weingart. She had normal APGAR scores right after birth, but about 30 minutes later, doctors began to notice that she was "floppy" and was having trouble breathing. Knowing that something was not right and that they had done everything they knew how, they flew her to Children's Mercy Hospital in Kansas City. Once there in the NICU, they ran all kinds of tests imaginable. Emily had weak muscle tone and had difficulty sucking. The geneticist, Dr. David Harrison, did a chromosome analysis and gave us the news: Emily had PWS.

While I wanted to go home and crawl under the covers just for a few days, John hit the ground running. Within the next few days we were in contact with parents of children with PWS, doctors, hospitals and PWSA (USA). Through all of these people, we were able to deal with Emily's syndrome in the most effective way that we could. We also had another daughter, Elizabeth, who was 22 months older than Emily, so we had to learn how to balance the needs of a young "normal" child with the demanding needs of a child with a disability. This is one of the hardest things to do and to this day, two more daughters (Sara and Annie) later, we are still learning that! — ***Nancy Weingart***

View From the Home Front

Sponge Bob Band-aids and a Broken Eyebrow

I am a very focused person. "Too focused," my husband says. So it is not surprising that I find myself often obsessing about the syndrome. Or as my husband so lovingly calls it... "OATS." Which probably comes from his military background and the need to make everything an acronym.

Anyway, I obsess, I obsess, I obsess.

I read e-mails about PWS. I surf the net for research articles about PWS. I talk to doctors about PWS. PWS, PWS, PWS... . And all too often, I forget to just stop and enjoy life, my family, my children, the world!

It is always Nicholas who finally snaps me out of it. Yesterday was one of those moments....

I was sitting at our kitchen table finishing up discussions with our OT, Becky. She had just completed a therapy session with Nicholas and was recording our info into her laptop. As I was talking to her, Nicholas climbed up into my lap. He began to study my face carefully. I am continuing to talk and trying to ignore him at the same time.

He then says, "Mama, your eyebrow is broken."

"Yes, honey," I say, completely unaware of what he just said.

"Mama, your eyebrow is broken," he says, this time a little louder.

"Yes honey," I say, this time a little more impatient and still unaware of what he has just said.

"Mama, your eyebrow is broken." He says once again. Only this time he takes my face into his hands and looks me in the eyes. Nodding, he says yet again. "Mama, your eyebrow is broken."

I finally stop and listen to this poor boy and realize that he is absolutely right. My eyebrow *is* broken. When I was a child, I fell off my bed and split my eyebrow on the night stand. I was taken to the hospital for a handful of stitches, leaving my eyebrow permanently split, or "broken."

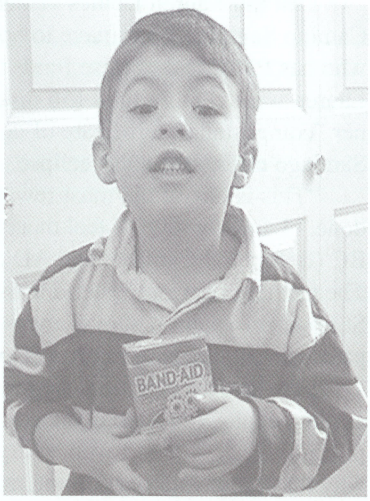
I look at my son and laugh. "Yes, Nicholas, Mummy hurt her eyebrow when she was a little girl."

"I fix it!" he cries enthusiastically, and runs into the kitchen.

I continue on with my obsessive need to live, eat and breathe PWS. I'm still talking to Becky, completely unaware of what my son does next.

He carefully opens the kitchen drawer... rrrrrccccrcckk.

He reaches for the band-aids, the Sponge Bob ones, not the regular ones!



Nicholas, who has PWS, with his Sponge Bob band-aids

He carefully opens the package and removes the band-aid. The one with pink Patrick Starfish wearing a pair of green and purple shorts. His personal favorite. He carefully removes the backing. He runs over to me, climbs into my lap carefully holding the precious dressing, trying to ensure it does not stick to itself.

As I drone on about nothing important, he sits up on his knees, faces me and carefully places Patrick the Starfish smack, dab onto my broken eyebrow. A perfect placement. Marcus Welby, M.D. could do no better.

"All better!" he says proudly. And finally I am silenced from my droning by this amazing child who gets it.

My mouth hangs open, I am completely speechless. The blue plastic band-aid taped carefully to the few remaining hairs of my eyebrow has paralyzed me. My obsession is over at least for a few seconds. My son is looking lovingly at me like he has just cured the world of all disease and I realize....this is what's important.

It only took a 3-year-old child and a Sponge Bob band-aid to open my eyes.

Lisa Peters
Georgetown, Massachusetts

We Remember Bob Olson


Bob Olson

It is in sadness that we bid farewell to Prader-Willi California Foundation President Bob Olson. Bob will be remembered for his love of his family and his dedication to our cause.

In retirement, Bob chose to become involved and to do his best to promote the good of the Foundation. He joined the Board of Directors in 2002 and served as board president the last 2 years. (Bob's wife Betty had in years past been a member of our Board of Directors.) Two weeks prior to his death, many of us had the privilege of being with him at our annual meeting in Long Beach.

At his memorial service, we learned what a wonderful husband, dad and grandfather Bob was. His hobbies included golf and building radio-controlled aircraft.

Bob is survived by wife Betty, three daughters (including Barbara, who has PWS), and five grandchildren.

Lisa Graziano, Executive Director, Prader-Willi California Foundation and PWSA (USA) Board Member

View From the Home Front

The Media Discover PWS Newsmakers

By Lota Mitchell, Associate Editor

Drs. Prader and Willi first identified and described Prader-Willi syndrome in 1956. Almost 50 years later, the media have made the same discovery. Below are just a few examples of what is popping up all over the country.

* **Jennifer Christiansen**, 15, Washington, appeared on a segment of ABC's Insider in November, as did **Maribel Rivera**, California, in June.

* **Payton Smallwood**, 7, Illinois, was featured in a newspaper article about the benefit Music Fest held for her.

* **Andy Maurer**, 46, South Carolina, is fast becoming the perennial PWS celebrity. After *People* magazine published an article, the local NBC-TV station did a feature on Andy, PWS and his beloved horseback riding. He was also interviewed by CNN for Paula Zahn's show, along with **Dr. Suzanne Cassidy** and **Mercedes Rivera** and her family.

* "On Q," a Pittsburgh PBS show, featured **Rana Awwad**, 13, from Saudi Arabia, who has been a patient at the Children's Institute. **Dr. Jeanne Hanchett** was also a part of the program, explaining PWS.

* **Ginny McMahon**, Virginia, daughter of Gibson and Aris McMahon, at only 8 months old starred with her story and picture in the magazine *CARING, National Association for Home Care & Hospice*.

* **Pam Keddie**, 38, New York, was written up in a newspaper article about her weight loss of a couple hundred pounds, successful residential placement, and participation in Special Olympics.

* **Austin Ayotte**, 6, Maine, who was recently diagnosed with PWS, was the focus for a local newspaper story.

* **Trevor Ryan**, 15, California, was mentioned in a Los Angeles newspaper article about a friend of his, Ronnie Raffaniello, 16. To earn the coveted Gold Award, the highest rank in Girl Scouts, she had taken on the task of raising awareness about Prader-Willi syndrome.

* CSI Las Vegas, without consulting PWSA (USA), had a story line about a young man with PWS who died of overeating. Some e-mails from those who saw it indicated that while it did briefly show extremes, they felt on the whole it was well done.

Yet, with all the media exposure that PWS has had in 2005, the familiar comment still comes back, "Prader-what? I've never heard of it!" And so the quest for awareness continues…

Trevor Ryan (left), who has PWS, with friend Ronnie Rafaniello

PWS May Mask Underlying Hypothyroidism

By Carolyn Loker, Young Parent Mentor

In my conversations with parents from the Young Parent Mentoring Program, PWSA (USA) e-mail support/information group and PWSA (USA) medical database survey, it has become apparent that hypothyroidism may occur more than we realize.

The hypothalamus stimulates the pituitary gland to release a chemical that stimulates the thyroid to produce thyroid hormone. The causes of secondary hypothyroidism (hypothalamic hypothyroidism) are failure of the pituitary gland to secrete the chemical to stimulate the thyroid gland, or failure of the hypothalamus.

Growth hormone (GH) and gonadotropins (FSH and LH) deficiency result in short stature and sexual infantilism in those with PWS. Hypothalamic dysfunction is the cause of such deficiency and depending on the degree of dysfunction, other hormones such as TSH that normally stimulate the thyroid gland can also be decreased.

According to the PWSA (USA) medical database survey, out of 301 respondents in the 0-5 population, hypothyroidism was reported in 7% and was slightly higher in older people with PWS. In the general population, hypothyroidism is stated to occur in less than 0.14% of those ages birth to 22 years old.

All states are mandated to test thyroid levels (blood draw) during the newborn screening process, but not all states perform a complete thyroid profile (Total T4, free T4, T3, TSH). Some states only check TSH level. Testing only for TSH can miss hypothalamic hypothyroidism.

The problem is that PWS may mask an underlying hypothyroidism which only can be diagnosed via a simple blood test. The clinical picture may not be recognized because of the low metabolic rate, weight gain and sleepiness — characteristics of both PWS and hypothyroidism. Since hypothyroidism is tested via a simple blood test, I believe that we should ask physicians to check our children for hypothyroidism. Also, children may not respond as well with growth hormone therapy until thyroid levels are normalized. You may want to ask your endocrinologist to check a **complete thyroid profile, which encompasses Total T4, free T4, T3 and TSH,** prior to and after starting growth hormone. Information about hypothyroidism may be found at www.Endocrineweb.com

Carolyn Loker is president of PWSA (USA) and heads the Young Parent Mentoring Program. She and husband Jim Loker, M.D. are the parents of Anna, who has PWS.

Sibling View

The Brother Who Was An Answered Prayer

"How are you and your brother alike?" I ask my older son Josiah.

"Well, we both like red."

"What else?"

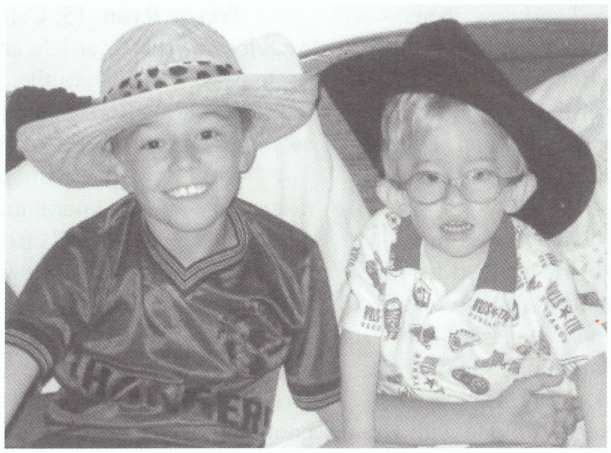
"We both like balloons."

"And?"

"We both like bean bags."

"Keep going."

"We both like to have Daddy all to ourselves, and we both like to wrestle — mostly with Daddy!"



Big Brother Josiah, 9, with his brother Nathaniel, 2, who has PWS

It is hard for him to remember these similarities when his baby brother Nathaniel pulls his hair, pinches him and hits him. There is definitely that rise of sibling rivalry in the air as the two of them grow up together. Whenever they are playing, my older son forgets his younger brother's age is 2. He often complains, "Mom, he's hitting me! Mom, He is trying to take my __!" It is amazing to me that the age span of 7 years doesn't seem to help counter these natural inclinations. You would think there would be *some* level of understanding in that age gap. Alas, they are just brothers, and that is all either of them understands.

My older son, two years before our younger son's conception, asked for, and even prayed for, a baby brother. When we would say his nightly prayers, he would continually ask God to bring him a brother.

When I did finally become pregnant, I decided that I had to be carrying a girl, since my pregnancy symptoms were so unusual. When I said as much, my son would indignantly reply, "No, Mom, I asked God for a baby brother!" He would not allow me to say anything different.

Unbeknownst to me, however, he was right and knew deep down inside that his prayer was answered. He spent the months of my pregnancy talking into my belly and saying, "Hey, when are you coming out of there? I want to see you!" He would then dream up all of the things he was going to do when his baby brother came. All my husband and I could do was just stand by and watch this drama unfold, unable to change his mind.

When our second son Nathaniel was born, he had almost no tone. Like so many other parents, we sorted through multiple appointments and health issues in which our older son Josiah oftentimes had to participate. We tried to balance our special son's needs with giving our older son some extra attention, and maybe it helped, because he rose valiantly to the occasion as any proud, big brother would. He helped carry his baby brother's diaper bag, pushed his stroller, and got his bottle for him. Even now, he helps me by playing with him, talking to him, learning sign language and reading to him.

He also tries to help by explaining more than he should to all of the therapists and doctors that we see. However, because of this adoration, his baby brother reciprocates the love by trying to be just like him. In fact, his big brother's name was one of the first words he tried to say. Even though our son was born under that curtain of sadness reflective in such a birth, all we heard from our older son was, "See Mom, I was right! It was a boy!"

Despite his elation, having a brother with PWS has, of course, changed our older son's life in some unexpected ways. What is it like being a big brother to a child with PWS? Well, in the words of Josiah himself, "I can teach him chess, if he wants to learn it." Then in the next minute he complains, "He always wants to do what I do!" He also says having a brother with PWS is "more painful when he pulls my hair and bounces on my ribs."

Although funny, these reflections of life with his baby brother have nothing to do with PWS. To him, PWS is just a minor road block, not a warrant for a lack of ability. It is all just a matter of time before his baby brother can accomplish his next goal. To him, and to us, the possibilities are endless. We look forward to the day when he will walk, run, and ride a bike. When he does, both boys will still be the best of friends, and continue to have a lot in common. One will always be the other's answered prayer.

Kim and Martin Kufus live with their sons in Floresville, Texas.

The Chuckle Corner

Don't Call Us, We'll Call You

My son Dusty, age 29, who has PWS, recently went to the emergency room for overdosing on water. It was scary, his sodium level had gotten dangerously low.

The next day his sister Penny called to talk with him. After a few minutes she asked Dusty if a nurse was in the room as she would like to ask a few questions about what was going on with him. Dusty told her no one was in the room. Penny asked him to buzz the nurse so she could talk with her.

"I can't," Dusty said.

"Why not?" Penny asked.

"Because I'm on buzzer restriction," he responded.

Penny burst into laughter as she could only imagine why that happened.

Susan Jacobs, Orange Park, Florida

State Department of Insurance Complaints: Getting Medical Bills Paid Without the Hassles

By Pattie Kelley-Huff

Life with a special needs family member presents enough challenges with day-to-day care without the hassles of constant fights and appeals with your insurance company that are energy-draining and time-consuming. There is an alternative to the appeals process with the insurance company that is often unknown to the insured, can be far more effective, and has more leverage than the insurance company appeals process; namely, the filing of a complaint against your insurance company with your state department of insurance (DOI).

I have found far more success getting legitimate medical expenses paid by using the DOI complaint process than exhausting the insurance appeals process. Hiring a lawyer can be expensive; it can take a very long time for your case to be placed on the docket for a hearing and with no guarantees regarding the outcome. I learned there is no fee to file a complaint with your state DOI. Again, there are no guarantees, but if you understand your insurance coverage and which expenses should be paid by the company, you probably have a good chance of the DOI advocating on your behalf.

In a nutshell, the DOI is a state agency funded by your state tax dollars. Its job is to license insurance companies, ensure that state mandates regarding insurance are adhered to by the insurance companies and to investigate and make determinations of complaints filed against them, as well as look for troubling trends of unacceptable practices and try to prevent them. DOI has the ability to recommend action to the insurance companies and can impose sanctions and fines, if necessary.

One of the advantages of utilizing the DOI complaint process over the appeals process within the insurance company is that there are statutes that determine the length of time an insurance company may take to respond to a complaint and subsequent communications exchanges. I have had the insurance company take months to decide if they will pre-authorize a medical procedure or equipment.

The DOI in my state, Illinois, allows no more than 45 days for the insurance company to respond to a complaint. Typically, one would file a complaint after payment has been denied, but in the case of a plan that requires pre-authorization, I have had success in filing a complaint when a pre-authorization was not granted or was stalled for an unreasonable amount of time.

I have filed numerous complaints with the DOI and have been successful in determinations in my favor in every single case. In two cases, the DOI imposed daily fines for unlawful practices until the insurance company paid.

One of the folks at the DOI said that insurance companies make millions, if not billions, of dollars because they expect some folks will not fight a claim, don't stand their ground for the duration of the appeals or complaint process, and ultimately either pay the claim or allow their credit to be affected if they are unable to pay.

It's amazing how willing providers are to work with you and the DOI when they know you are actively involved with an open complaint on file with the DOI. In cases when the providers' representatives did not have the ability to prevent credit bureau reporting, the DOI representative contacted them directly and was successful each time in preventing a bad mark being placed on our credit report.

Complaints are not difficult to file, but you must be sure before you file the complaint that it is legitimate and deserving of your complaint. You need to be thorough in your explanation about the situation, e.g., the procedure/expense, the reason for denial of payment. I make it a practice when I file a complaint to provide all letters, bills, letters of medical necessity, all documentation, anything that is relevant to the complaint, to avoid delays at the DOI when trying to get the file together and complete to present to the insurance company.

Even though it may take a little extra time to submit all this information initially, it will save you much time in the future when they will inevitably ask for it anyway. This also prevents your insurance company from answering the DOI with what I like to call a "garbage response": e.g., "We never received the bill," "We never received the claim," or "The claim wasn't filed in a timely fashion." If you send all bills, claims copies, denial letters, etc., you pre-empt these frustrating replies by simply pointing out that all documentation was provided when the complaint was filed. *[Ed. Note: Be sure to keep copies of all items you send.]*

The response times and how one files a complaint, i.e., Internet versus mailing, vary from state to state, but essentially DOIs serve the same function and *are* the agency that has some leverage and power over insurance companies. It has also been my experience that, since I have been filing complaints for about two years now, I have had a much easier time getting services, procedures or equipment pre-approved and paid in a timely fashion. I would venture to say that the insurance companies probably track trends as well, and when they realize certain members will routinely hold them accountable to their obligations, they tend to be more attentive, since they know they have nothing to gain with this particular person. The squeaky wheel gets the oil.

Below is a link to find each state's department of insurance:
http://www.healthinsurancefinders.com/cr_state_department_of_insurance.html

I wish everyone who has medical expenses in this country was aware of the mostly untapped potential of their local state department of insurance. I urge you to utilize your state department of insurance that is funded by your hard-earned tax dollars to help improve your ability to get claims paid and minimize your hassles.

Pattie and her husband Scott live in Winthrop Harbor, Illinois, with their son Christopher, 4, who has PWS.

International View

Education & Research about PWS A World Away

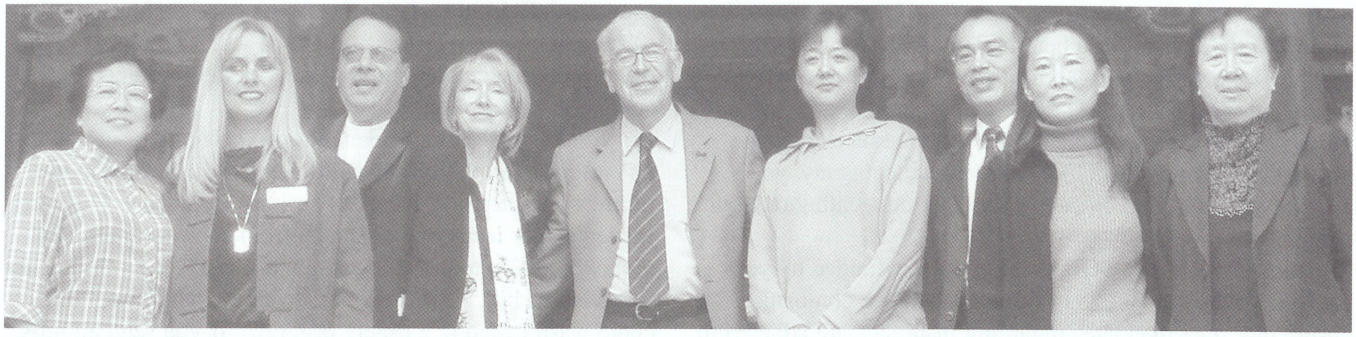
By Janalee Heinemann, Executive Director

China, Japan and Taiwan asked that Pam Eisen, Dr. Shaun Pei Lin and I come to their countries to educate their PWS families and physicians. In China Dr. Moris Angulo and Dr. Dick Scwaab from the Netherlands joined us for China's first symposium on Prader-Willi syndrome. It is mainly thanks to Pam's hard work that this major first step was made in China, where the political system does not allow families to form an organization, and most PWS babies probably die in infancy. In a population of millions, there are only a few known children with PWS.

TOKYO, JAPAN — I was struck with how their very low-fat, low-sugar diets allowed children with PWS so much more freedom than in other parts of the world. The Japanese and survival of our children with PWS is very daunting. China is not at all in the same social, cultural and political realm as Japan and Taiwan.

Local coordinators did invite a PWS family who traveled 10 hours by train with their little boy and the grandparents. Dr. Angulo (bless his heart) did an examination on the boy and gave the parents advice. As in all developing countries, everyone was very eager to get information and grateful that PWSA (USA) encourages them to translate our materials in their own language.

TAIWAN — Pam and I were overwhelmed by our reception in Taiwan. Because they believe our visit there 2 years ago helped the country get growth hormone therapy approved for children with PWS, we were publicly thanked at several hospitals where we spoke. Taiwan Foundation for Rare Disorders (TFRD) made us honorary advisors and gave us special business cards.



Organizers and presenters gather during the first-ever Prader-Willi Symposium held in China

don't have high-calorie snacks available in most places, and what food a child can sneak is typically very low in calories.

After speaking at a Toyko hospital, we went with Dr. Tomoko Hasegawa to various destinations. We visited the school of Kai Tsuura, an 11-year-old who has PWS, where we observed him in some of his classes and at lunch. Kai's mother Takako is chief of the Tokyo Bureau of PWSA-Japan. His school also has another girl with PWS. At lunch he proudly put on a cap and uniform and helped serve others. Viewing vegetables piled high on their plates, plain white rice, light soup, and tea (not just for Kai, but all children), I could see why diet control is not such a big issue. At our hotel, I was pleasantly shocked to see a boy of about eight making a lettuce salad for breakfast.

We met a group of PWS parents at the school for lunch and discussion. One mother clutched a worn, printed copy of our Medical Alert material from our web site. She told us that this was her "bible." All three countries are very eager to get our new Medical Alert booklet translated into their languages. Later we visited their supportive living program where adults with PWS live in their own apartments that are food free and come together in a common area for meals and socialization. One woman supervises the apartments with fairly minimal assistance.

CHINA — Although Dr. Song and Dr. Chow, physicians who helped organize this ground-breaking, two-day symposium on PWS were also wonderful, their situation is very different, and the task that lies ahead regarding the diagnosis

While in Taiwan, a study on CoQ10 and growth hormone therapy (GHT) was reported by Dr. Jia Waei Hou, of the Medical Genetics and Metabolism Department at Chang Gung Children's Hospital. I am working on clarifying certain aspects of the research and will give our members a more detailed report in the next edition of *The Gathered View*.

Dr. Lin reported that 70 children have been diagnosed with PWS since they started their three-phase screening protocol in 2000. They do M-PCR first – if positive, they do a FISH test to see if there is a deletion. If FISH is negative, they do a microsattelite analysis to detect UPD. What was surprising is that only 10% have UPD (compared to the usual 25%). Before growth hormone therapy was approved by the government in December 2003, only four children were on GHT. Currently, 23 patients are on GHT.

Due to a strong cultural and religious perspective in medical care of compassion and treating the whole person, combined with the emphasis as a society on education, new PWS groups receive strong support from TFRD. Our two PWSA (USA) trips there have been possible thanks to TFRD's funding. Pam and I predict that Taiwan will soon be a leader in PWS care in Asia.

Asia continued on next page

Upcoming Vote Needed To Permit Board Votes Via E-mail

In accordance with PWSA (USA)'s bylaws, the Board of Directors is notifying all members (via the website and this issue of *The Gathered View*) of an upcoming motion, to be voted on by the members at the next annual meeting, to amend PWSA (USA)'s articles of incorporation so as to allow the Board to vote via e-mail.

PWSA (USA) is a Minnesota corporation. Under current Minnesota law, the board of a nonprofit corporation may vote via e-mail, but only if the corporation's articles of incorporation so provide (see Minn. Stat. § 317A.239). PWSA(USA)'s articles of incorporation were written in 1977, when personal computers were barely on the horizon and e-mail simply did not exist. Article X was added in 1990 to permit votes by mail, but votes via e-mail were not specifically authorized at that time. Because PWSA (USA)'s Board members are located throughout the country, the Board regularly conducts much of its business via e-mail. Formal votes, however, must be delayed until the next time the Board meets in person (just 2 times per year). To enable the Board to conduct its business more efficiently, the Board recommends that the membership of PWSA (USA) amend the articles to allow the Board to vote via e-mail.

An amendment to the corporation's articles of incorporation requires passage by the members present at the annual meeting, or those voting by proxy. According to PWSA (USA)'s bylaws (see Article IV, Section 4), proxy votes must be mailed directly to the National office, and received no later than 14 days prior to the annual meeting.

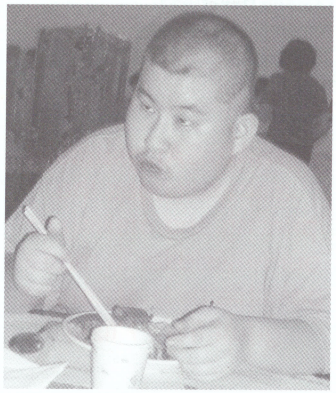
Notice of Motion To Amend The Articles of Incorporation of PWSA (USA)

Pursuant to Article IV, Section 7.d. of the bylaws of PWSA (USA), all members of PWSA (USA) are hereby notified that the following motion (which has been submitted and seconded as indicated below) will be voted upon by the membership at the next annual membership meeting, scheduled to occur during the 28th annual PWSA (USA) conference in Grand Island, New York, July 19-21, 2006:
MOTION: [name of person] moved and [name of person] seconded the adoption of the following resolution:
RESOLVED, that Article X of the Articles of Incorporation of Prader-Willi Syndrome Association shall be deleted in its entirety and replaced by the following:
ARTICLE X.

The Directors of this corporation shall be authorized to make decisions and transact business for said corporation by written action signed, or consented to by authenticated electronic communication, by the number of Directors that would be required to take the same action at a meeting of the Board at which all Directors were present.

Asia - *continued from page 14*

Helen Chin and her son Neu-Neu, who is typical of a person with PWS who is high functioning, traveled with us. At at a vegetarian buffet lunch, he returned to the table with a bowl piled high with lettuce and other vegetables. I was impressed that he did not try to get the higher calorie foods — until his mother decided he had too much. When she scooped some of his salad onto her plate, I saw that at the bottom of the bowl he had hidden salad dressing an inch thick! It made me appreciate once again that even when our social and political realities are different, PWS is the same all around the world!



Neu-Neu eating his salad

Psychiatrists - *continued from page 3*

these meetings, and it was also the first time that PWSA (USA) had a presence at AACAP.

Behavior DVD well received

Feedback on the Pittsburgh Partnership DVD, *Food, Behavior & Beyond – Practical Management for the Child and Adult with PWS*, has been universally positive. The Ontario group ran out of DVDs at their conference, and the California group also sold out! The DVD is available for order from the PWSA(USA) web site.

We at PWSA (USA) especially want to thank the Gerald J. and Dorothy R. Friedman New York Foundation for their funding support for PWSA (USA)'s involvement at this conference. Together, we are making a difference!

— Janalee Heinemann, Executive Director

Correction

Due to misinformation supplied to *The Gathered View*, Dentist Tom Hughes was incorrectly identified as an orthodontist in our Nov.-Dec. 2005 issue. We regret the error.

Contributions

Thank you for Contributions through November 2005

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

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