

The *Gathered View*

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

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

PWSA (USA) Statistical Teasers

By Barb McManus & Janalee Heinemann

To date, 1,747 families have responded to our first survey/questionnaire, but **only 259 have responded to the second questionnaire.** We hope you will consider completing the forms at www.pwsausa.org/population, if you haven't already done so, or call 800-926-4797 to request a paper copy. We have reported on the first medical survey and some of the specialized surveys -- with more to come. (See page 5 for our statistics on **seizures**.) Here are "teasers" from the second survey, but we would like larger numbers of responses to get a more accurate perspective on PWS issues. If you have any problems filling in the forms, you can contact Barb McManus at bmcmanus@pwsausa.org or call 800-926-4797 with your questions.

In the general population, most choking deaths are ages 1-4 where in PWS the average age of death from choking was 24 yrs.

Choking: Of 259 respondents, 40 (15%) reported serious choking episodes. Of those, only one was under the age of five. (Note: In the general population, most choking deaths are ages 1-4 while in PWS the average age of death from choking was 24 years.) Of the 40 incidents, 22 required the Heimlich maneuver. Hot dogs, grapes and chicken were the most common causes, but other substances such as hard candy, steak, and a toothpick were also mentioned. Risk factors include:

- poor oral/motor coordination
- poor gag reflex
- hypotonia
- hyperphagia
- decreased mastication (chewing)
- sneaking food and swallowing quickly to avoid getting caught

Age of mother at birth of child: Of the 244 responses, the majority of mothers were in their 30s with 21 over the age of 40.

Born to mothers in their 30s = 34 had UPD, 68 deletion, 3 translocation, 3 imprinting, and 16 type of PWS unknown.

Born to mothers in their 40s = 15 had UPD, 3 deletion, and 3 unknown.

Body temperature average: The average temperature is 97-98 degrees, but in our survey, PWS parents report that 59% were above or below the average with most below.

Hypothyroidism: Of 259 responses, 134 children with PWS were tested for thyroid disorders. Of those, 26 tested positive for hypothyroidism. Nine tested as hypothyroid before they started growth hormone therapy (GHT) and nine after starting. The rest were not on GHT.

Sleep disorders: Reports on ages six years and above:

- Daytime sleepiness = 34.5%
- Narcolepsy = 4.0%
- Cataplexy = 2.5%

Locking up food: Of those responding to this question, 76 said they did lock up food, and 55 said they did not lock. Before age five, 27 families started locking, but 55% said they did not start locking until ages 10-19.

Psychosis: In this category, 106 responded. Of those, 16 have had at least one psychotic episode. About half of those (7) have had more than one episode. It is interesting to note that there was an equal number of those with



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Cole Lombardi, aka spikey

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USA
**PRADER-WILLI
SYNDROME
ASSOCIATION** *Still hungry
for a cure.*

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

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User Name: pwsamember
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Note: If you have difficulty logging in, please contact info@pwsausa.org.

E-mail Support Groups:
We sponsor nine groups to share information.
Go to: www.pwsausa.org/egroups

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Deadlines to submit items to *The Gathered View* are: Dec. 1; Feb. 1; Apr. 1; Aug. 1; Oct. 1

Executive Director's View

Photo by Eric Hilton



Craig Polhemus

Let's Be Social

For 34 years, PWSA (USA) members -- families, friends, and professionals affected by the challenges of PWS -- have supported each other. Members provide each other with inspiration, information, and understanding. **We all belong to the Prader-Willi family.**

One example is our New Parent Mentoring program. The "crown jewel" of membership benefits, the New Parent Mentoring service initiated by Carolyn Loker and Janalee Heinemann matches a family just beginning to learn about PWS with a family that, through life experience, has become an empathetic expert.

Newsletters and national and chapter events have always offered venues for mutual support. Over time the PWSA (USA) website, our e-mail support groups, and e-mail announcements have come to play an ever-increasing role in helping members inform and support each other. New methods for interaction and mutual support keep evolving.

I'm sure most of you have heard something about Social Media -- including Facebook and MySpace (social networking), blogs (commentary), Twitter (to share "What's up?"), YouTube (video sharing and commenting), Second Life (virtual reality), Flickr (photo sharing), and webinars

(online presentations or seminars). PWSA (USA) will soon be offering a few structured webinars on topics of interest to parents.

A rapidly growing, supportive, friendly, and enthusiastic fraction of our membership now uses Social Media to make friends, socialize, and sometimes take joint action in advocacy or fundraising.

If you are at all curious, you might want to take a look at just one free service such as Facebook. Thousands of people have commented on or joined PWS-related pages. It's easy to try it out. One way is to start at www.facebook.com, which offers a free and simple registration process. Once you get to your Facebook home page, use the Search box at the upper right to search for me or for Michael Alterman of Atlanta. Michael, whose brother Andrew has PWS, is a PWSA (USA) Board member who has volunteered to coordinate a PWSA (USA) presence on Facebook.

Or you can start out at www.tinyurl.com/aqhu72. Michael's personal fundraising page, and register for Facebook from there. There you will find Michael's personal fundraising goal for PWS (he started at \$5,000 and is more than halfway there -- so I expect him to meet this goal and set a higher one soon). From there or from Michael's or my personal Facebook pages, you will find a link to the PWSA (USA) "Cause" page where many other donors have pitched in as well.

The PWSA (USA) Cause page includes a brief note from me with a picture of the student

leaders at Eastside High School in South Carolina who raised over \$200,000 for PWSA (USA) crisis and family support programs. And, demonstrating how different forms of Social Media interact, there is also a link to a video on YouTube where you can see and hear the cheering crowd when this stupendous achievement was announced at halftime of an Eastside football game.

What do people do on Facebook? They socialize. After mutually selecting Facebook "Friends" permitted to see what they write, they tell what's going on in their lives. Or they post pictures of themselves and their families and friends. They share information. They advocate. They chat. They empathize. They support causes they care about.

So if you sometimes feel alone, if you would like more contact with those facing challenges similar to yours, or if you are simply curious, Social Media might be worth checking out. Perhaps I will see you online!

 **CHUCKLE CORNER**

One morning my daughter was trying to get my granddaughter, Aimee, age 5, to hurry and finish breakfast so she wouldn't miss the bus. Aimee's reply was "I'll hurry tomorrow, Mommy."
~ Beverly Cobin
Freehold, NJ

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Medical and Research View – Ask The Professionals

Medical Questions & Answers on PWS

By **Janalee Heinemann**

Director of Research & Medical Affairs, PWSA (USA)

Here are some questions that have come to PWSA (USA) and answers from members of our Scientific and Clinical Advisory Boards.

Question: Is low sodium possibly related to the medications?

I had a call from the mother of a 31-year-old male. In Sept. he appeared to be seizing and had trouble breathing. He did not test out as having seizures, but was very low in sodium and magnesium. They put him on magnesium and brought it up, but cannot get his sodium above 130. Right now it is 124. They have restricted his fluid intake and salt his food more. He is on a LOT of medications. His behavior is now wonderful, but is his medical problem due to reaction to one or a combination of meds? He is on:

Loratadine 10 mg a day, Oxcarbazepine 600 mg 3x a day, Chlorpromazine 50 mg 2x day, Chlorpromazine 100 mg 2x a day, Buspirone 10 mg 3x a day, Benztropine 1 mg 2x a day, Fluvoxamine 100 mg 2x a day, calcium 600 mg 2x a day, magnesium 3x a day, plus a multivitamin.

Answers: (1) You are absolutely correct! His low sodium may be due to the 1) oxcarbazepine, 2) fluvoxamine, and/or 3) chlorpromazine, or a combination of all of the above. Low sodium can cause seizures. It would be helpful to know which meds were added last, as there may be an additive effect leading to the problem. There is also the possibility of endocrine or renal problems causing the low sodium, but I suspect it is the medications.

If oxcarbazepine is the culprit but is proving to be very helpful to the behavioral control, Dr. Gourash and I have had excellent success adding low dose Lithium which causes free water loss through the kidneys; the added benefit of Lithium is mood stabilization. This must be done with someone who has experience using Lithium, as there are other side effects. Oxcarbazepine can be used successfully with positive effects on mood and behavior if side effects are monitored and carefully addressed.

This fellow is on a *lot* of meds, increasing the potential for drug-related side effects.

Janice Forster, M.D.

Pittsburgh Partnership

(2) Every single person with PWS that I put on **oxcarbazepine** (Trileptal) developed lower sodium when the total daily dose exceeded about 900-1200 mg. The sodium may stay in the safe range, but it always goes down some. I am certain that the problem with this young man is primarily the oxcarbazepine, but the other medications could be contributing. The physician in charge may wish to adjust the oxcarbazepine dose downward and recheck the sodium with each dose change. The effect is dose related but not necessarily linear.

I had this experience with about 12 patients. Even if the sodium is not dangerously low, you have to keep checking it. It can drift down slowly over weeks or months to a dangerous level. Physicians are not used to how sensitive people with PWS are to the effects of oxcarbazepine on the sodium and need to be very

vigilant. I feel much safer if the patient is also being treated with Lithium.

We also had 2 patients (one had an atypical deletion; the other had an imprinting center deletion) who developed low platelets. One was dangerously low and recovered as soon as we stopped the oxcarbazepine.

Linda Gourash, M.D.

Pittsburgh Partnership

Question: Insurance is denying paying for Synagis to prevent RSV. Aren't our infants more at risk for RSV due to their increased respiratory risk? Shouldn't insurances be required to pay?

Answer: Synagis is indicated for the prevention of serious lower respiratory tract disease caused by respiratory syncytial virus (RSV) in pediatric patients at high risk of RSV disease such as infants with bronchopulmonary dysplasia (BPD), infants with a history of premature birth (≤ 35 weeks gestational age), and children with significant congenital heart disease. All other use would be considered off label.

Synagis costs about \$1,000 per shot every month during RSV season. Insurance companies do not like to pay for an expensive medicine that is used off label. It is possible that if the cost comes down we may see more off label use of the medicine. It would take studies that would show not only safety of the shot but also a significant benefit to convince drug companies to lobby FDA to include PWS in the indications. With the small numbers of infants with PWS it would be difficult to demonstrate a significant benefit.

We need to keep an eye on

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Medical and Research View – Ask The Professionals

Q&A, continued from page 4

this, but in the meantime we need to emphasize good hygiene in all infants with PWS. RSV is spread by contact. Parents need to wash their hands and use alcohol cleanser to reduce not just RSV but all infections in infants with PWS.

James Loker, MD

*Pediatric Cardiology
Medical Director
Bronson Childrens Hospital*

Question: How common are seizures with PWS? What type?

Recently, my granddaughter was diagnosed as having seizures. The last few times were considered as tonic (also called Grand Mal or a Convulsion) seizures, but she did not jerk as I thought tonic seizures characterized. She only dropped to the floor unconscious with muscles restricted. They did not last very long, but it sure was scary. After some testing, we found out that a characteristic she often has is, in fact, a partial complex seizure. When excited and happy, she will cross her eyes, twist her tongue and move her fingers in a strange way. When this happens, she can be pulled out of it by just saying her name. We always thought this was her way of showing happiness and were surprised that this was considered a seizure. Is this common with PWS?

Answer: From our PWSA (USA) medical data base of 1,747 respondents:

- Ages 0-5 = 6% seizures
- Ages 6-18 = 9% seizures
- Ages 18+ = 13% seizures
- All ages with UPD = 6% seizures
- All ages with deletion = 12% seizures
- All ages with imprinting = 3% seizures

All ages with translocation = 26% seizures
PWS like or type of PWS unknown = 13% seizures

Seizures are less common than with Angelman, and those with PWS who do have seizures do not often have the classic epileptic grand mal seizures. Many just have subtle changes in behavior as with your granddaughter or just phase out for a while, so many seizures may go undiagnosed.

Question: With all of the new alternative supplement and vitamin treatments, is there any risk in giving your child high doses? Is 5000 mcg/day of vitamin B12 safe to give?

Answers: (1) Regarding the B12 question, it is not a good idea to have excess quantity of any specific agent, particularly a vitamin. Although the B vitamins are not fat soluble (such as A, D, E, K) and should be excreted if in excess if the metabolic and physiology of an individual is not altered, we cannot say this with certainty in PWS. Therefore, I would not recommend it, particularly in developing infants (PWS or not PWS). B12 treatment can mask specific types of anemias so one would need to follow blood counts as well.

The use of nutrition supplements (particularly vitamins such as folic acid, another B vitamin) and its effect on gene expression and activity (which we know is already altered in PWS) could further complicate the gene alterations in PWS. For example, adding excess folic acid may decrease gene expression in living cells, further complicating the altered genetic network and gene-gene interaction in PWS based on the one carbon

metabolism pool in living cells.

Therefore, I would not recommend megadoses of B12 in PWS subjects, particularly infants; it is an area of concern for me regarding long term effects for the PWS individual. We should be cautious.

I also talked with a neurologist here at Kansas University Medical Center about megadoses of B vitamins and particularly in children with PWS. He said 5000 mcg/day is high. They treat their adults (non PWS) with once/month B12 injections (1000 mcg) but did not think it would cause problems although he was concerned about the massive dosage (5000 mcg/day), particularly in children. He said excess B6 treatment can lead to permanent neurological damage. He would opt for measuring plasma homocysteine levels initially to gauge the need for folic acid or B12 treatment before use.

Merlin G. Butler, MD, PhD, FFACMG

*Professor of Psychiatry, Behavioral Sciences and Pediatrics
ABMG Certified Clinical Geneticist and Clinical Cytogeneticist*

(2) There can be consequences from treating someone who does not have B12 deficiency with high doses of B12 (such as are given with B12 injections). I am recommending to have the B12, folic acid, and methylmalonic acid levels checked, and if there is evidence of deficiency then B12 injections would be indicated. If not, I would not recommend the injections, but oral B12 would be OK as not as much is absorbed as with the injection.

Jennifer Miller, M.D., M.S.

University of Florida

Expanding our World of Research

The Prader-Willi Syndrome Association (USA) is sponsoring the **1st International Conference on Hyperphagia**. The puzzle of hyperphagia (the extreme unsatisfied drive to consume food) will take center stage this June 4 and 5 at an unprecedented scientific conference at the Hyatt Hotel, Inner Harbor Baltimore, Maryland.

The **1st International Conference on Hyperphagia** will for the first time gather together experts from around the world to discuss developments and unanswered questions of appetite control and hunger. Discussion will center on such areas as genetics, behavior, addiction, neuroimaging, endocrinology, animal models, and metabolism.

The unique structure of the program will include representatives from the National Institutes of Health, the pharmaceutical industry, the academic world and experts from several rare or uncommon disorders which have hyperphagia as a hallmark characteristic. A limited number of parents will also be able to attend. Attendees will participate in discussions focusing on developing a series of recommendations for the "Best Avenues" for future research.

"Oppressive hyperphagia plagues not just those with Prader-Willi syndrome but also those affected by such syndromes as Alstrom, WAGR, Fragile X, and Bardet-Biedl," according to Janalee Heinemann, PWSA (USA) Director of Research and Medical Affairs.

Oops!

The 2009 Professional Providers Conference will be June 4 and 5 at the Hyatt Regency-Inner Harbor, Baltimore, MD – *not* June 3 as previously stated in the January-February Gathered View, in our email announcements, and on our web site. We apologize for this error. Correct information including a Call for Presenters (due April 1) can now be found on our web site, www.pwsausa.org/Conference/2009/provider.

George Bray, M.D., from the Pennington Biomedical Research Center will be the keynote speaker on Thursday night, June 4th. Dr. Bray has spent his career focusing on the problems of appetite control and has written a multitude of articles on appetite control, obesity and diabetes.

"Prader-Willi syndrome has been described as the Window of Opportunity for study into the perplexing problems of Hunger," says conference co-chair James Kane. *"Hunger is a cornerstone in the foundation of the critical worldwide public health problem of obesity. The study of the extreme condition in such disorders as Prader Willi syndrome, Alstrom, WAGR, Fragile X and Bardet-Biedl will yield results applicable to the general population."*

For more information about this 1st International Conference on Hyperphagia, go to www.hyperphagia.org. ■

For information about the **annual 2009 PWSA (USA) Scientific Conference on Prader Willi syndrome** to be held all day on **June 4th** (the day before the hyperphagia conference) and our **Providers Conference** that has been extended to 1 ½ days **from June 4th to June 5th**, go to www.pwsausa.org. ■

Statistics...continued from page 1

deletion vs. those with UPD, which is not what has been reported in the literature in recent years. Previous reports found a much higher incidence in UPD. The age breakdown of the *first* psychotic event was:

- Age not reported = 1
- Ages 5-10y = 4
- Ages 11-15y = 3
- Ages 16-21y = 5
- Ages 21-30y = 2
- Ages 31-40y = 1

Picking: Regarding skin picking, 157 responded

- Yes = 61%
- Mild = 78%
- Severe = 17%
- Rectal = 5% ■

Only 259 have responded to the second survey. We need your help to improve the world's largest medical database on PSA!

Call for Nominations for PWSA (USA) Board of Directors and Volunteers for Committee Service

The source of PWSA (USA)'s strength lies in its membership - parents, extended family members, professionals, and others committed to promoting research, education, and support for families affected by Prader-Willi syndrome.

We are currently seeking candidates for the 2010-2012 Board of Directors and volunteers for Committee service. Please contact us if you or someone you know possesses the qualities necessary to be an effective member of the Board of Directors:

- Ability to listen, analyze, think clearly and creatively, work well with people individually and in a group.
- Membership in PWSA (USA).
- Commitment to serve a 3-year term (unless nominated to fill a shorter term).
- Willingness to attend Board and committee meetings and other special events. Ask questions, take responsibility for a given assignment, support the Association as generously as your financial resources allow and assume shared responsibility for generating resources to meet Association goals, open doors in the community.
- Develop skills you don't already possess such as understand financial statements, cultivate and solicit for funds, cultivate Board members and other volunteers.
- Possess honesty, sensitivity to and tolerance of

different views; a friendly, responsive, and patient approach; community-building skills; personal integrity; a sense of values; concern for the Association's development; a sense of humor.

What will you gain in return for your service?

- A sense of pride as you work to better the lives of all persons affected by PWS.
- Have input into decisions and policy-making that affects persons with PWS.
- Increase your knowledge about PWS and its treatment and management strategies
- Increase your exposure to professionals who work with individuals with PWS.

To nominate yourself or someone else, please contact Leadership Development Committee Co-Chairs Lisa Graziano, Mary K. Ziccardi, and me by emailing info@pwsausa.org, or by calling the PWSA (USA) office (800-926-4797 or 941-312-0400), or by faxing to 941-312-0142. The deadline for nominations is April 10, 2009.

To continue to grow as a vibrant, effective organization, PWSA (USA) also needs volunteers for fundraising, advocacy, and family and research support, among other areas. If you are able to free up some time to help, please fill in our volunteer form at www.pwsausa.org/help/volunteer.asp. There is no deadline, as volunteers are always welcome.

Thank you! ■



A World of Opinions on PWS

By Janalee Heinemann

We are pleased to announce that now available to PWS families is the outcome of a meeting held in Toulouse, France, in October 2006. The consensus paper is called: "Comprehensive Care Of Patients With PWS - Consensus, Questions And Future Directions". From this report, "Recommendations for the Diagnosis and Management of Prader-Willi Syndrome" was published in The Journal of Clinical Endocrinology and Metabolism. The article summarizes the consensus that came out of the meeting. The 31-page article is available to be downloaded at: <http://jcem.endojournals.org/cgi/rapidpdf/jc.2008-0649v1>

I presented at this meeting as did several of our PWSA (USA) scientific and clinical advisory board members. It was a worldwide effort to work on a consensus report regarding the management of care for Prader-Willi syndrome. A special thanks goes to Dr. Maité Tauber from Toulouse for coordinating this major event. ■

Visit our newly improved web site for more pictures, regular updates and more...
www.pwsausa.org

Awareness Month – May 2009

May is a great time to increase awareness about PWS! Not only is it a beautiful time of year, it's also a time when we can all work together to increase the awareness of PWS in our communities, families and friends. The best way we can be advocates, role models and supporters of our loved ones with PWS is to Get Involved and help shine the light on PWS. The more people are aware, the more accommodating and understanding they may be. Most parents desperately want their children to be welcomed, given accommodations for their needs, and understood not just by the immediate family, but by everyone.

Reading about why you're needed doesn't make a difference.

Thinking about doing something doesn't make a difference.

Getting started DOES make a difference.

Here are some ideas to help you get started spreading the word during Awareness Month – May 2009

• **Get on a First Name**

Basis: Knowing your local and state leaders is one of the most important steps in an advocacy awareness program. How many elected officials can you name? How many know you? Send them letters and get to know their policies. Help them become more aware of PWS by sending an email. Who?

1. Top elected officials in your community
2. The local aides of your federal Senators, Congressperson and State Legislators
3. The president of the biggest employer in town
4. A business leader involved with the local Chamber of Commerce
5. The co-ordinator of a major nonprofit coalition or community foundation in your area
6. The leader of the largest local religious institution
7. A reporter who covers local human interest stories and nonprofits
8. School Superintendent and President of the School Board

• **Write Letters to the Editor:**

"Letters to the Editor" is the most widely read section of the newspaper. Select an issue that

matters to you that can relate to PWS, such as the need for respite care/Medicaid issues, and address it in a Letter to the Editor. If several parents in the town write a letter, some are bound to be printed and *that* would be quite a lot of exposure to PWS.

• **Set Out Community Collection Boxes:** Designed for Chapters--select a child with PWS to be on your collection container and make a list of the stores and businesses that would be willing to set them out on their check-out counters for you. Chapters can purchase the containers from PWSA (USA) for \$3.56 and keep all the money that is collected. Be sure to contact your city/county government for rules pertaining to collection boxes for nonprofits.

• **Plan School Activities:** One school's "Spirit Week" raised more than \$200,000 for PWSA (USA). We have a manual available for anyone willing to begin such an amazing fundraising and awareness opportunity. Just give us a call. Just think of these great school-based ideas – PJ Day, Backwards Day, Celebrity Day when students pay 25 cents and dress up according to the theme;

an assembly program about PWS and other medical issues that some of the students may have at your particular school; an art poster project illustrating ways to be kind to one another, to be hung in the hallways. Be sure to work with your school administrator to implement these ideas.

• **Host a Gold Rush:** With the price of gold soaring, "gold rush parties" are all the rage. Invite your family, friends and neighbors to your party, bringing their gold, silver or platinum and precious stones, old class rings or broken pieces of jewelry to contribute. The money received from the party can be donated to PWSA (USA) toward whatever support fund you wish. Brochures providing information on PWS can be available at the party.

• **Give a presentation:** We have created a PowerPoint® presentation that gives an overview of PWS, all set and made just for you! That's right – just for you! Schedule time to give a presentation to service clubs, a group of friends, colleagues at work, or whoever else you want.

Awareness, continued on page 9

Awareness...

continued from page 8

• **Increase visibility:** PWSA (USA) will have available new promotional items to help with visibility which you can order. Watch the website for further information.

• **Plan a fundraiser or send letters:** It's not too late to send letters or plan a simple fundraising event. Sample letters are ready for you, and ideas are a phone call away. Don't forget, you can also create a web page at www.firstgiving.com/pwsausa.

You can also visit www.pwsausa.org and click on "Awareness" to find tools you can use. Of course, you can call PWSA (USA) to share or discuss ideas, too. Any month is a good month to combat PWS and increase awareness. **But nothing shows strength like working together, and together we can make May a powerful month, if we all do just ONE thing!**

While the ideas in this article can be put into action **one person**

at a time, our vision extends far beyond the individual. It is a simple game of numbers...

A community of friends
Fellow employees at work
A chamber of commerce
A neighborhood
A school
A church
A club

And as the information about PWS spreads across the nation,

*imagine a day when
everyone is kind and
understanding to
our people with PWS*

*imagine a day when
all educators will provide
positive support to our children*

*imagine a day when
there is no question about
supplying insurance for
support services*

*imagine a day when
there are wonderful
job training facilities
dedicated to people with PWS*

Imagine... ■

Congressional Awareness

One sign of how effective PWS Awareness Month has been is House Resolution 55, introduced in the first full week of the new 111th Congress.

Sponsored by a bipartisan group of Representatives including Edward Royce and Jane Harman, both of California, H. Res. 55 would grant federal recognition to PWS Awareness Month while also supporting increased funding for research into the causes, treatment, and cure for Prader-Willi syndrome.

"PWS Awareness Month is much more than ceremonial," notes Craig Polhemus, Executive Director of PWSA (USA). "Twice as many Americans with PWS are undiagnosed as those who are diagnosed. They and their families lack access to the information, support, and resources that they need to cope with the many challenges of PWS. Congressional recognition of PWS Awareness Month could have a real impact on their lives."

"Our community is committed to supporting this important resolution," said Lauren Schwartz Roth, President of the Foundation for Prader-Willi Research. "We strongly believe that by raising awareness and supporting research, this resolution will be vitally important in finding the answers that will help our loved ones lead long healthy lives, free of the burden of PWS. We also believe that PWS research will lead to breakthroughs in the understanding of many other illnesses, including childhood obesity."

To contact your Representative and urge him or her to consider co-sponsoring H. Res. 55, call (202) 224-3121 or go to www.house.gov, where you can use your zip code to identify your local Representative.



PWSA (USA) is included in the Combined Federal Campaign. If you work for the Federal government and its agencies, use CFC ID No. 10088 to designate PWSA (USA) to receive donations. Questions? Call PWSA (USA) at 1-800-926-4797.

From the Home Front **A Kitty Cat Caretaker**

We are very proud of what our daughter Tricia, 28, with PWS, has accomplished. All her life she has loved and cared for animals. She has a job at a small animal farm, where it takes a special person to relate to the rats, mice, crickets, hamsters, guinea pigs and cockroaches. The work is dirty but necessary, and she really likes working there. In addition, she does cat sitting for residents of the Masonic Village (retirement



Tricia and Bear, a client's cat

community) where my husband and I live. Her business card states, "I'll pamper your pet at your home." She was recently featured in the village's newsletter, which commented that "The cats couldn't be in better paws." The 20-pound kitty in the picture is a hard one to catch, but he knows and comes to Tricia willingly. There is a life after school for our kids!

*~Sherrie Letcher
Elizabethtown, PA*

Being Accepted

My son Colby, 6 1/2 with PWS, has "tics". He does the whole arm flapping, thumping of the chest thing when he's REALLY excited. He didn't walk until he was about 3 1/2 and would sit and rock until then. Even after he started walking, he preferred to stand and on occasion would stand and rock. Then he switched from rocking to arm flapping when he became excited. When he does this, we usually just put our fingers on his



shoulder as a reminder that the behavior isn't really acceptable, but, honestly, it doesn't help 100% of the time. We had Colby evaluated by specialists, and it was decided it was just one of his quirks.

Last year Colby transferred into a regular school, into the functional skills program. Toward the middle of the school year the teacher asked to see me. I was freaked out, thinking he'd done something wrong. When I met with her, she told me the following story: That day on the playground during recess a group of third graders came up and started talking to Colby. They then asked the teacher if it was okay if Colby could play with them. The teacher said yes, but watched them all with reluctance. She said that the older boys took Colby in as one of their own, tossed him the small hackysack and included him in their group. He continued to play with them every day during recess for the remainder of the school year.

The teacher kept me updated on their "group" progress and told me that the older boys would come to the teachers and tell them, "Did you know that Colby knows all of his numbers? Did you know that Colby knows all of the shows on Nickelodeon? Did you know that Colby knows how to win the Freddie Fish computer game!!? We didn't know he was so smart!"

That, coming from a group of third graders who I feared would

only ridicule my poor, loving Colby, really made my school year.

~Catie Whitney, mom to Colby, Bryce (5) and Riley James (5 months) Lusby, Maryland

Justice Faith is 5!!

The past 5 years have been kind of a whirlwind. Without the help and support of my e-mail group, PWSA (USA), and GOD I don't know how we would have survived.

On the day Justice was born we had no explanation why she was so weak and why she would not eat. Our ambulance ride to Childrens brought out every possible fear that new parents have. Our emotions went from great joy to terrible grief



Justice Faith and Decoy

in such a short period of time. Our stay in the NICU brought no answers

either. We were sent home (by my request) without a diagnosis.

As the test results came back, we were relieved to find out that Justice had PWS-UPD (out of the 3 things they tested for this was by far the best news). Hearing the diagnosis was a relief and like being kicked in the stomach all at once. I had read so much about PWS, and the thought of it frightened me. All of the info on the Internet painted a picture of an out of control child with little or no hope of a "normal" life. (Don't trust everything you read!)

Justice is anything but an out of control child. She is polite and extremely eager to please, she does not have any eating issues yet, and she does not exhibit any behavioral issues. I do know this can change at any time, and IF it happens, we will be ready because of our faith, the

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Home Front...

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e-mail group and PWSA (USA).

The past 5 years have taught me so much!! We have become involved in a whole new world that until Justice Faith I had turned a blind eye to. We are constantly running to therapy, a doctor appointment, or an IEP meeting or making sure that the Individual Education Plan is being followed. I never knew that so many parents

had to deal with all of this. I took for granted that everyone was like us and their infants met all of their milestones on time. The only time you went to a Dr. was for a check-up or maybe an ear infection, and who would of thought that you would actually have to argue about your child not having a cookie. This was a whole new world that we were suddenly plunged into, and because of it we are better people.

Justice Faith is and always will be a source of joy and inspiration to everyone she comes in contact

with. Her infectious smile and sense of humor will bring a smile to even the grumpiest person. She has a light inside of her that just seems to glow and attract others to her. My 4 older children are so proud of her; when she does something new, their pride and love for her seems to take on a life of its own. She has brought out the best in all of us. John and I are truly blessed with 5 perfect children.

~Kristi and John Rickenbach
Spring Lake Park, MN

■

Monthly, Like Clockwork

Like most nonprofits, families, and businesses nationwide, PWSA (USA) has suffered from the economic downturn. Because of generous support from so many families and friends, our preliminary financial results for 2008 show a small surplus – but only because we **reduced expenditures by nearly 10%** (\$145,750) compared with 2007. The 2009 budget approved by the Board in October calls for **reducing non-research expenditures by another 9.3% during 2009**, unless our revenue drop this year is smaller than projected.

To sustain our programs, PWSA (USA) relies on thousands of loyal donors. We now offer an even easier way to give: **Regularly Scheduled Recurring Donations**. If you can afford to make even a small contribution each month, PWSA (USA) will be ever grateful. You can set up these monthly donations through the “Give” tab at the top of www.pwsausa.org, then click on Donate Now. On behalf of the thousands of families we serve each year, Thank you so very, very much! ■

Celebrating Pam, Our “Iron Mountain Laurel”

Knowing she would not survive pancreatic cancer, Pamela Eisen wanted, not a funeral, but a celebration of life. In January sons Jeremy and Benjamin saw to it that her wish was granted. In addition to her family and friends, many members of the Prader-Willi family converged on Camp Hill in the middle of Pennsylvania—in the middle of a snowstorm—to say goodbye to one of their own and to indeed celebrate the life of this extraordinary woman, President of the International Prader-Willi Syndrome Organization (IPWSO), and mother of Gabriella, 28, with PWS.

From Italy came Giorgio Fornasier, opera singer, past president of IPWSO, and father of Daniele, age 30, with PWS, to thrill everyone with a program of song. Janalee Heinemann, past Executive Director of PWSA (USA) and current Director of Research and Medical Affairs, spoke of the many trips she

had made to international destinations with Pam. Dr. Shuan-Pei Lin, Taiwan, talked about Pam’s accomplishments with IPWSO.

In 2001 Pam volunteered to be the parent delegate from the U.S. to IPWSO, and 2 years later she was elected president. This slim, fragile-looking woman whose gentle graciousness belied her “steel magnolia” interior (or maybe “iron mountain laurel” since she was from Pennsylvania), poured her energy, compassion, and intelligence into helping those in many corners of the world who lacked the information or resources to deal with PWS.

When Gabriella was born, Pam kept a journal of her feelings, wondering if the sun would ever shine again. It did. She helped the sun to shine in many dark corners of the world. The glow of her love for her daughter lit up the lives of many dealing with the effects of PWS. She will be missed.

Donations in her memory may be made to PWSA (USA). These will go into a fund for international efforts, unless otherwise designated. ■

Chapter View

Dr. Ann Scheimann, Assistant Professor of Pediatrics, Pediatric Gastroenterology and Nutrition at Johns Hopkins Hospital, and member of the PWSA (USA) Clinical Advisory Board, was speaker for the November meeting of **PWSA of New Jersey**. Her topic was "From One End to the Other: How PWS Affects the Digestive System (and What You Can Do About It)."

PWSA of New England held its First Chapter Dance in November for families and friends, an afternoon of fun and dance with raffle prizes, music, cold drinks—and food-free! Its Annual Holiday Party in December was also food free and quite successful. The kids create more crafts and are less distracted by the snack table. Parents find it less stressful because they do not have to be so vigilant and can enjoy more socializing.

Prader-Willi California Foundation held its annual General Educational Meeting on Nov. 8 in Sacramento. There were speakers for different age groups on topics such as Special Needs Trusts, improving parental negotiation skills, and Vocational Service planning for adults with PWS. Janice Agarwal, physical therapist and PWSA (USA) board member, addressed the physical and sensory deficits of the young child caused by PWS and strategies to improve them.

PWSA of Ohio announces that once again Recreation Unlimited will have a summer camp experience exclusively for adults and children ages 8 and up who have PWS. The camp will run from Sunday, June 7, through Friday, June 12, with crafts, talent show, dancing, tower climbing and more. For information and/

or to register go check their web site at www.recreationunlimited.org. Click on Camps and Programs. Scroll down to Specialty Camps and click. Or you may call Laura Smith at the camp (740) 548-7006. **PWSA of Ohio** also held their Fall Weekend Camp there.



Dr. Moris Angulo brightened the holidays of **Prader-Willi Alliance of New York** by throwing a party for families with children with PWS. He booked a talented magician, with arts and crafts and light refreshments also. Dr. Angulo will be a speaker for the New York Conference 2009, to be held in Albany May 1-2, as well as Dr. Harold Van Bosse from Shiner's Hospital in Philadelphia, Dr. Gregory Cherpes from Pittsburgh's Children's Institute, and Janalee Heinemann from PWSA (USA).

The New York chapter has been establishing area support groups, and here is one participant's view: "I can't tell you how helpful it has been to me just to get together with other families and talk. I have already gleaned words of wisdom from the parent of an adult with PWS, had lots of laughs over shared experiences, and have even had a few 'aha'

moments that have prompted me to look further into services for my son. I have left every meeting smiling, if not laughing, and have enjoyed getting to know some of you that I may not have ever met otherwise. And those are just the positive benefits to ME... I believe that building this web of support will be more for [my son's] benefit in the future."

Barb McManus, our Director of Family Support, says:

"Our state chapters offer parents and families a great service, but not all states have chapters. Even if your state has a chapter, you might live in a remote part of the state or the chapter meets seldom if ever for support and networking with others.

"PWSA (USA) is offering resources and help for chapters and individuals wishing to expand local support with regional support meetings. If you are willing to help organize these meetings, you might be a lifeline for the families that need help -- and discover you also find support in the process. Please contact me at our offices or e-mail bmcm Manus@pwsausa.org if you are interested in regional support groups." ■

What's YOUR chapter doing?
E-mail GV Editor Lota Mitchell at info@pwsausa.org.

Sibling View

In her book Audition: A Memoir Barbara Walters says: *"Sister: I thought for a while that is what the title of this memoir should be because it was my older and only sister, Jacqueline, who was unwittingly the strongest influence in my life. Jackie was three years older than I, but all our lives she*

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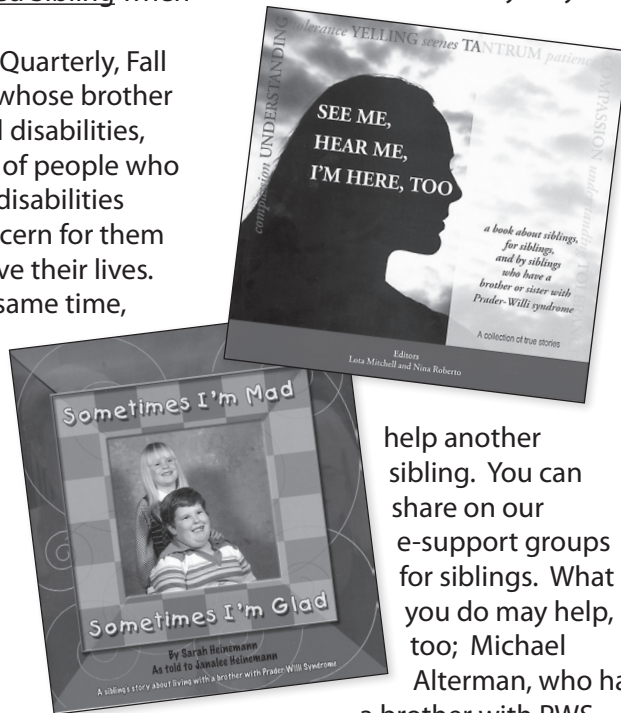
appeared younger."

She went on to say "Much of the need I had to prove myself, to achieve, to provide, to protect, can be traced to my feelings about Jackie," who was developmentally disabled. Barbara expressed the wish that she had read Jeanne Safer's The Normal One: Life with a Difficult or Damaged Sibling when she was younger.

In the Ohio DDQuarterly, Fall 2008, Cathy Allen, whose brother has developmental disabilities, notes that millions of people who have siblings with disabilities have immense concern for them and want to improve their lives. She writes, "At the same time, we 'normal ones' often feel confused, burdened, overlooked or even pushed aside when we offer our assistance. Many of us are deeply desirous of the empathy and companionship of others who share our experiences. When adult siblings are educated, empowered and connected with one another, they become better advocates for their families and for themselves. We want and need to know how to help our brothers and sisters, how to interact effectively with our parents and

with the system. By reaching out to each other, we improve our own lives and the lives of our siblings."

If you are a sibling of someone with PWS, you are encouraged, regardless of your age (child, teen, or adult), to write for the Sibling View about your experiences growing up or as an adult (e-mail to info@pwsausa.org). What you have to say may



help another sibling. You can share on our e-support groups for siblings. What you do may help, too; Michael Alterman, who has

a brother with PWS, serves on the PWSA (USA) Board of Directors.

And what you read may help you. PWSA (USA) sibling books "Sometimes I'm Mad Sometimes I'm Glad" is for children, and "See Me Hear Me I'm Here, Too" written by siblings is for teens and adults. ■

Ed. Note: Would you like to join one of our e-mail support groups? Here's how:

Go to www.pwsausa.org/egroups, click on the list you are interested in, then on the following page click on the top link which will say something like, for example:

To subscribe to this list - send an email to: PWSA-USA-TEENS-subscribe@yahoo.com

Counselors Corner

Good news from the Social Security Administration! PWSA (USA) Executive Director Craig Polhemus reports the SSA recently praised our new packet of Supplemental Security Income (SSI) resources as "incredible information" for families to use in the application process. The resources, designed by PWSA's crisis program, include forms your doctor can fill out, a template for a parent's journal, and tips on working with the SSA. A number of parents have reported moving smoothly through the SSI application process using these resources. So, if you are in the process of applying for SSI, please download and use the resources posted at: www.pwsausa.org/ssi.htm. If you do not have a computer and would like the resources mailed to you, please call us.

While you are on the web, take a few minutes to explore our brand new crisis pages on the PWSA (USA) website www.pwsausa.org/support/crisisteam. These pages provide helpful resources for how to prevent and respond to crisis situations involving behavior problems, finding or keeping residential placement, and school challenges. This is an exciting next step in our crisis program because it allows parents and families to access crisis resources 24/7. Let us know what you think and anything you would like us to add by e-mailing efarrar@pwsausa.org. See you next time in Counselors Corner! ■

~David Wyatt and Evan Farrar



The Roll Of The Genetic Dice

By Janalee Heinemann

PWSA (USA) Director of Research & Medical Affairs

Because of some tension within one of our e-mail support groups, I wrote and posted the following:

Dear parents,

I am aware there has been communication around the issues of food control and behavior. The big question – which has not really changed much over the years—is how much control our children have over their food seeking and behavior. Those whose children have fairly minimal problems in this area often think it is a matter of good parenting skills. This leaves parents whose children will go to great extents to get food and who have major behavior outbursts feeling guilty, misunderstood, and isolated.

I, too, thought it was more of a matter of learning skills that worked with PWS because after I came into our son Matt's life when he was seven and got myself educated on PWS, I was able to turn his weight and behavior around. But after years of taking crisis calls and observing that many of the parents I came to know who were educated about PWS and doing it all right still sometimes had children with PWS who would go to any extent to get to food and would have frequent destructive outbursts, I became more interested in our research defining genetically why the dramatic variances. As we learn more about how much of a deletion there is, where the deletion occurs, etc., we are beginning to understand why there are such dramatic variances within the syndrome.

Also I have come to appreciate that some children who do not test out PWS but are "PWS-like" or have hypothalamic obesity (what we call "Acquired PWS") have even more problems with the drive to seek and consume food. Hyperphagia, the extreme drive for food, is a characteristic of other conditions and birth defects besides PWS--which is why we are doing a hyperphagia conference this June so we can look outside our own PWS box to learn more about the hunger and food drive.

Meanwhile, I hope we can respect the fact that each parent is doing the best they can. If your child is doing well, give yourself a pat on the back – but also thank God that your child received a better genetic hand than some other children who have PWS. ■

The following are a few of the responses:

Thanks, Janalee. Sometimes no matter how far we go...to the ends of the earth...our children still have issues. My son is 7 and spent 2 months in Pittsburgh [at the Childrens Institute] already!!! My every waking moment is PWS and how to manage our household to PWS proof. It is a dice roll....how about not just deletion but disomy? [Janalee: Yes, there are also large variances within the disomy – UPD group.] What are we to think? PWS is PWS...as I always say- *we are all in the same river just in different boats without paddles!* (our paddles are National and the crisis intervention!) I think we are ALL great parents to just even be on this group and reach out and seek help.

Well said, Janalee. I am an educated, extremely proactive parent who has gone nearly to the ends of the earth to help my son and he is still a massive food seeker and tantrummer over food. For him, it started extremely early (before age 2), before he could even walk. Yes, we have measures in place following Drs. Gourash and Forster's recommendations, etc. ...I

firmly believe in the underlying genetic differences that will someday explain some of the reasons some individuals with PWS are doing better than others, just as some are born with better tone or better speech...Why did we have to start locking at age 2.5 while others not until the teen years or never? I have wondered that a thousand times over, often prefacing the thought with "what did I do wrong to make him this way"...Of course parental involvement, dedication and interventions are crucial, and I have high hopes for my son's future; but I also have had to accept (with great difficulty) that some of the outcomes for my son are beyond my control and fall under the roll of the genetic dice.

Thanks for the reality check, Janalee!! I feel so badly for those families on television shows where the child is so PWS-like, but does not test positively for it and the doctors and TV show host are bashing the parents for letting their young children become obese. Without a clear-cut diagnosis, they are not being truly supported. ■

Contributions

Thank you for Contributions in December 2008 & January 2009

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

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