



The *Gathered View*

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



Lauren (see our new calendar)

**HO HO HO
Happy Holidays!**

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With Visions of Sugar Plums

By *Janalee Heinemann, Executive Director*

It's OK to have visions of sugar plums dance in the dreams of your child with Prader-Willi syndrome — but how do you keep them out of their mouths? With food so plentiful at holiday times, it is important to plan ahead to prevent problems.

Halloween — Although you'll receive this edition of *The Gathered View* after Halloween, to prepare for next year you may want to go to our web site to download the wonderful Trick or Treat Tips written by Vickie Fetsko from Ohio.

Thanksgiving — This holiday, so wrapped around food, can be a reminder to our families of what they are *not* thankful for. Thanksgiving with the relatives can be disastrous without careful planning ahead. If your child is old enough, rehearse the "rules" before that day and come to a mutual agreement on what your child will be allowed to eat. You can barter: i.e. "Do you want a little extra turkey and dressing, or do you want a piece of pie as your special treat?" Make sure you know what everyone is bringing, so there



Our Sugar Plum Fairy is Molly (see our new calendar)

are no surprises on what the choices will be. It is much easier to do this ahead of time than to get "caught" with an upset child arguing at the table in front of relatives.

Make sure all attending know the rules and agree to cooperate. See that someone at all times is clearly in charge of your child

Sugar Plums continued on page 12

A Holiday Alert



Last holiday season, three of our teens and adults with PWS (and a fourth unconfirmed) died unexpectedly, due to food-binging episodes that led to necrosis of the stomach wall and a perforation (tear) in the stomach. In three of the four, the person with PWS was slim, so there was no great concern about weight gain. All were all in festive group situations, where "everyone was watching, which meant no one was watching."

Keep in mind that someone with PWS who is slim does not have total food control. Too many temptations, the lack of feeling full, and the high pain threshold create the potential for filling the stomach dangerously full.

Because our children and adults with PWS have many food-binging episodes — most without such disastrous results — we think that probably other factors play into this life-threatening scenario. But until our research on deaths is completed, we feel obliged to forewarn parents, grandparents, and caregivers of this potential threat.

Prader-Willi Syndrome Association (USA)

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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA) unless so stated. Medical information published in *The Gathered View* should not be considered a substitute for individualized care by a licensed medical professional.

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

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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

Members Only: Check our web site www.pwsausa.org for Special Opportunities Limited to Members

User Name: pwsamember Password this issue: leaf

Note: if you have difficulty logging in to this 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://www.pwsausa.org/only>

Nominees wanted for PWSA(USA) Board of Directors

Membership on the Board is open to any member of the organization, including parents, caregivers and professionals. Extended family members are also welcome (three grandparents and one aunt are currently officers or directors).

What does the Board do? This is an exciting and challenging time for PWSA(USA), as awareness of the syndrome is growing, research opportunities are expanding and requests for information and crisis intervention are accelerating. The Board works with the Executive Director to manage PWSA's current operations and to plan for its future.

How many seats are open and what is the term of office? Twelve Board members each serve a 3-year term and can run for 3 consecutive terms. At the next election (summer of 2006), 4 seats will be open.

What is the expected time commitment? Board members are to attend the annual conference and all in-person and telephonic board meetings. Two in-person board meetings are held each year – one in winter (usually in January, at the national office in Sarasota) and one in summer (at the annual conference, usually in July). At least two Board meetings occur each year (usually in April and October) via conference call. Each member is to serve on one or more committees and participate in any meetings and conference calls involving those committees (see below for information on committees). Much of the Board's business is conducted via e-mail, so candidates are expected to regularly read and respond to e-mails and be comfortable with that form of communication.

What is the expected financial commitment? People who donate to nonprofit organizations such as PWSA(USA) often have an expectation that each Board member will demonstrate a meaningful financial commitment to the organization. Because our Board has always included members from a wide variety of financial backgrounds, we have never established a minimum donation requirement. Each Board member is responsible for covering his or her costs in attending the conference and Board meetings. If there is need, the organization will reimburse a member for a limited amount of his or her documented travel costs.

What qualifications are needed? The main qualification is a heartfelt desire to improve the lives of those with the syndrome and a willingness to work hard toward that goal. We welcome whatever expertise you might bring that could help the organization accomplish its work (e.g., science, medicine, business, public relations, education, law, social work, conference planning, technology, editing, etc).

How do I apply? If you are interested or want to recommend someone, please submit a brief description of qualifications for consideration to serve on the Board no later than April 6, 2006. Mail, fax or e-mail this information to:
PWSA(USA)

Attention: Carol Hearn, Co-Chair, Board of Directors
5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242
Fax: (941)312-0142 or e-mail: national@pwsausa.org

PWS In the News

People magazine published the feature we worked with them on, a story on Andy Maurer in their Sept 5th edition titled "A Deadly Hunger." Andy did an excellent job of telling his perspective of what it's like to live with the syndrome.

Money magazine published an extensive and positive story in their July edition about the Jeff and Kari Porter family. We thank this beautiful family for sharing so much of their personal life and finances with the magazine.

Dr. Phil Show did follow up on the program for which I sent information and contacts. It was taped, and should have aired by the time you read this. For the featured family, they chose a mother not known to us, but afterwards referred her to PWSA (USA) for education and support.

The **National Association for Home Care & Hospice** did a very positive, 6-page article (and front page) on PWS in their magazine, CARING. It features beautiful pictures of 8-month-old Ginny McMahon, daughter of Gibson and Aris McMahon, along with the family's story. It includes this from Aris, "And, through the wonderful support of the Prader-Willi Syndrome Association (USA) (www.pwsausa.org), my husband and I learned that the PWS information our doctors told us that awful afternoon was very out of date. The doctors failed to contact PWSA to learn the much more positive prognosis for infants being diagnosed today."

Other major television programs also in the works, but we'll wait to discuss them until they are "done deals."

— *Janalee Heinemann, Executive Director*

We Need Committee Members Too!

If you are interested in the work of PWSA(USA) but are not quite ready or able to seek Board membership, please consider serving on one or more of PWSA(USA)'s committees. We think it is helpful for a member to be on a committee prior to running for the board.

The PWSA(USA) Board of Directors oversees the following committees: Research, Publications, National Conference, Crisis Counseling, Office Technology, Finance, Fund Development, Endowment and Leadership Development. Each committee is usually chaired by a Board member, but often includes non-Board members. Face-to-face committee meetings are held in conjunction with the semi-annual Board meetings, but non-Board committee members are not required to attend these. Committee business is handled in the interim by telephone and e-mail communication. If you would like to serve on one or more of these committees as a non-Board member, please submit your name, qualifications, and the name of the committee(s) you are interested in to the address shown above.

2006 National Conference is
July 19-21, Grand Island, NY
(near Niagara Falls)



Working Together and Getting It Done

Carol Hearn

Wow! What a wonderful response we've had to our calls for increased financial support of PWSA (USA)!

You may know that our financial picture at mid-2004 was disturbing. We had an operating deficit of about \$32,000 in 2003, and by June 2004, were running an operating deficit of about \$65,000. With limited new dollars on the horizon, and program costs increasing, our finance committee was projecting a year-end operating deficit of \$40,000 or so for 2004.

Thankfully, through generous gifts of a number of donors and grassroots fundraising efforts of several families (some holding fundraisers for the first time), we not only managed to keep our head above water for 2004, but ended up with an operating surplus of about \$150,000. As of May 31, 2005, our Angel Fund donations are up as well (exceeding last year's same time total by almost 12%). So we have many reasons to be thankful.

That's the good news. The bad news is that we will likely sustain a loss in 2005. As we increase awareness and early diagnosis of PWS, the demand for our services increases — particularly the demand for crisis intervention, new parent mentoring, information packets and other inquiries to the national office via phone and e-mail. In addition, our Board has made a strong commitment to increase funding for research. The annual conference puts a great strain on our budget as well, particularly in years like this one, when there is no state chapter hosting or doing the fundraising for the conference.

Moreover, we have no assurance that the funding sources that came to our rescue in 2004 will recur in 2005. For example, one of our most generous unanticipated contributions in 2004 was a bequest — a wonderful, generous gift, but, obviously, not one that will be repeated in 2005. While we hope many of the folks who made donations or held fundraisers in 2004 will do so again in 2005 and beyond, we continue to operate from year to year with no guarantee that there will be enough money to continue supporting the broad range of programs that are so critical to our members.

Our Fund Development committee has a host of ideas on how to help PWSA (USA) raise the funds it will need to ensure that its vital programs (including research, crisis intervention, conference, mentoring, website, publications and the like) continue, but we will need your support every step of the way. Here's how to help:

- Host a Grassroots Fundraising Event for PWSA (USA): Grassroots fundraising projects come in all shapes and sizes — from golf tournaments and gala dinners to simple letter-writing campaigns. Anyone can be a grassroots fundraiser, particularly if you care deeply about the cause. If you are unsure how to get started (or ready to host an event!) please

contact Jodi O'Sullivan, our part-time director of community development (and loving aunt to a child with PWS) at comdev@pwsausa.org.

With input from fundraising families, Jodi has compiled a number of "how-to" guides to help you in implementing a fun and rewarding event. Spend a few moments talking with Jodi before you start planning — she may save you hours.

- Encourage Friends and Relatives to Donate Through the Valentine Research Fund Program, the Lose-A-Thon Program or Otherwise: The Valentine Research Fund program provides an easy way for you to encourage friends and relatives to donate to PWSA (USA)'s research efforts. Check the website for instructions on this and other donation programs.

Also, consider naming PWSA (USA) as a preferred charity whenever an occasion calls for donations, whether it's a sad occasion (such as a memorial) or a happy one (such as an anniversary, a birthday or a welcome retirement).

- Make Angel Fund and Other Donations of Cash, Securities and Needed Items: Angel Fund and other cash donations of all sizes are always appreciated, as are donations of securities. For in-kind gifts, the national office maintains a list of needed supplies and equipment.

- Obtain Matching Donations from Your Employer: This may be one of the most under-utilized resources available to our members. And it's so easy — you can double your gift to PWSA (USA) without incurring any additional cost. If your employer has a matching gift program, consider completing the simple forms necessary to apply for a gift matching your annual donation to PWSA (USA). If your employer doesn't have such a program, consider asking for a matching donation anyway.

- Help PWSA (USA) Make Contact With Foundations or Potential Corporate Donors: If you or someone you know could be helpful in putting PWSA (USA) in touch with such donors, or governmental agencies, please contact Janalee at the national office.

- Buy PWSA (USA) Calendars, Wrist-A-Bouts, Apparel, Publications and Other Items: The 2006 PWSA (USA) calendar — featuring our beautiful kids — is available! Thanks to donations from several generous sponsors, every penny of your calendar purchase goes directly to PWSA (USA), so buy them now to give to your friends, relatives and business acquaintances. The orange Wrist-A-Bouts have also been a hit.

Simply put, we wouldn't be here today without the past efforts and donations of hundreds of individuals just like you. Working together, just imagine the impact we could have on the future.

Passion Turns The Impossible Into Success

PWS Families across the country continue to use imagination and enthusiasm to raise money and awareness on behalf of Prader-Willi Syndrome. "Research whatever type of fundraiser you are doing, educate yourself about it and GO FOR IT," wrote Kelly Coats of Michigan.

Here are reports from some of the people who went for it. We thank them for their efforts.

Walk/Run Relays

Last spring, **Mike Vogrin** organized the **2nd Annual PWS Relay at Calvert Hall College High School**, where he is a teacher. Mike's nephew Oscar Hill has PWS. Mike's goal was to raise money and awareness for PWS, and "to get young people excited about reaching out to the greater community." He did both, pairing people with PWS with a "buddy" from one of the nine participating high schools, and netted \$10,500 "I was so proud of the high school students and their willingness to give their time and energy," he wrote. He credits Calvert Hall College High School, where the event took place, Maryvale Prep and Seton Keough High School for providing student leadership, PWS of Maryland-Virginia-DC, the local sponsoring chapter, and publicity help from radio DJ JoJo Girard, who told the story of his brother who had PWS and passed away a few years ago.

This was the first year for **Clyde's Run in Memory of Clyde Mays**, held this summer in Georgia. Clyde's mother **Hope Mays** wrote, "I wanted to raise money to add to the research fund after my son's death, and everybody in the community came together suggesting to do a run because Clyde was such a runner. [*Clyde, who had PWS, was 24 when he died in July 2004 of stomach necrosis.*] The 300 participants netted more than \$3,800. "We are already committed and started planning for next year," wrote Hope.

Golf Events

Kelly and Steve Coats netted more than \$20,000 in September with the **2005 Prader-Willi Charity Golf Outing in Honor of Christian James Coats**. "It was our way of helping out," wrote Kelly. "The thing that really made everything all worth it was when my husband gave his speech, Christian really went crazy clapping and signing 'more.'"

Pat Meakim organized the **2nd Annual Cal-Chip Charity Golf Tournament to Benefit PWSA (USA)**. This August event, held in Pennsylvania, brought in more than \$16,000. "It's definitely worth the time and effort," wrote Pat, whose daughter Bridget has PWS.

In Maryland, **Bill and Anne Vucci** held their **2nd Annual Prader-Willi Open in Honor of Maria Christine Vucci** on August 25 and netted more than \$23,000. The event included participation from gymnast Kerri Strug and "special mystery guest" Ted Koppel, host of TV's "Nightline."



Anne Vucci (second from left) and her parents, Gloria and John Pedevillano, with Ted Koppel, host of "Nightline" (center) and Bill Vucci (right) at the 2nd Annual Prader-Willi Open in Honor of Maria Christine Vucci

What It Takes

All agree that a core of enthusiastic people provide the help that brings success. "If it were not for the collaborative efforts of our 'Fun Bunch Team' of parents who accepted our 'Greater Cause,' the awareness and fundraising goals could never have been achieved," wrote Bill Vucci.

Don't be afraid to ask for help. "I should have been more forward in asking for help. When it was over, my friends, family and neighbors told me they would have helped more if I'd asked," wrote Kelly Coats.

Do something that's fun. "I would encourage anyone who was interested in raising awareness and funds for PWS to find something they enjoy and use that venue to help out," wrote Mike Vogrin. "Whether it's a bike race, a walk-athon, a golf tournament, the important thing is that you raise awareness in the process. The Prader Willi Syndrome Relay in Baltimore may not have raised as much money as other events, but because of the nine high schools that were represented, there are thousands of people who know about PWS who never heard of it prior to the event."

These fundraisers also suggest naming a person to build the event around. It helps to put a face to the reason for your efforts. "We also know the love and compassion our children bring out in others," wrote Bill Vucci.

— **Jodi O'Sullivan, Director of Community Development**

THE LOSE-A-THON IS COMING!

Have you been trying (or intending to try) to lose weight for some time now? We may have just the program for you! Check www.pwsausa.org in the upcoming months to learn how you can participate in the 2006 PWS Lose-A-Thon to benefit PWSA (USA). It's a great way to honor your friend or loved one with PWS while giving yourself a powerful incentive to achieve your personal weight loss goals. Sign up by January 2006, and pledge to reach your initial goal by May 1, 2006.

PWS Awareness Booth Attracts Hundreds of Physicians

By Janalee Heinemann, Executive Director and IPWSO Parent Representative

Thanks to a grant obtained by our international organization IPWSO, and our funding for materials from CIBC World Markets Miracle Day, we were able to co-host an awareness booth at a major endocrinology conference that was held in Lyon, France. It was a joint meeting of the USA's Lawson Wilkins Pediatric Endocrine and the European Society for Paediatric Endocrinology.

Our Prader-Willi syndrome awareness booth was an outstanding success. We estimate that a minimum of 600 endocrinologists visited us to pick up materials and ask questions. We gave out all 500 Medical DVD's and Medical Alert booklets, and all 300 growth hormone booklets, several hundred packets, various brochures and articles.

Dr. Phillip Lee, who is now in the UK, and was at the booth next to ours, wrote, "It was a great surprise to see you, Pam [Eisen, IPWSO president] and Giorgio [Fornasier, IPWSO director of program development] in Lyon — and an even greater surprise to see how popular PWS has become." Dr. Lee, who is on our Scientific Advisory Board, is now chief scientific officer at Immunodiagnostic Systems Ltd. It was great having him "next door" to our booth. If there was a growth hormone question that I was uncomfortable answering (e.g. questions on appropriate dosage), I could just take the person over to meet Dr. Lee.

Dr. Martin Ritzen from Sweden and Dr. Urs Eiholzer from Switzerland reported many comments on how impressed all were with our booth and the amount of educational materials we provided. We were the only non-profit booth at the entire conference. We had many compliments on both our national (PWSA-USA) and our international (IPWSO) organization, and many very grateful physicians from developing countries who were eager to get any materials they possibly could and to talk to us at length.

Information on PWS of Particular Interest

- **On Incidence Rates:** A study in Iceland of incidence rates confirmed the "one in 12,000 – 15,000" we typically quote. Researchers were able to get all the national records and determined the incidence from 1976-2000 was one in 13,500 live births. (Snjolaug Sveinsdottir – Reykjavik, Iceland)
- **Pituitary Size & Functioning:** From Italy, in analyzing MRI's, researchers found a reduction in pituitary size in 45/91 (49.4%), a complete absence in the posterior bright spot (PPBS) in 6/91 (6.6%) and other neuroradiological alterations in 10/91 patients (11%). Altogether, neuroradiological alterations were present in 61/91 (67%) – more frequent than previously reported. This supports the hypothesis of true multiple hormone deficiencies (GH, FSH, and LH) in the majority of people with PWS. (Lorenzo Lughetti, Verbania, Italy)
- **Increasing Genital Size:** From Zurich, Switzerland, Urs Eiholzer reports that children with PWS display a special form of combined hypothalamic and peripheral

Six Continents, 69 Countries

Thanks to Pfizer and CIBC World Markets Miracle Day, we were able to educate endocrinologists from:
China, Brazil, India, Greece, Bulgaria, Slovenia, Romania, Taiwan, Hong Kong, Portugal, Albania, Norway, Turkey, Saudi Arabia, Kuwait, France, U.K., Ecuador, Australia, Brazil, Indonesia, Israel, Argentina, Belgium, Cyprus, Switzerland, Sweden, Republic of Korea, Spain, Japan, Denmark, Russian Federation, Mexico, France, Thailand, Columbia, Chile, Italy, Indonesia, Netherlands, Iceland, Lithuania, Poland, Germany, Islamic Republic, Hungary, Czech Republic, Serbia, Austria, Ireland, Croatia, Canada, Philippines, New Zealand, Vietnam, Latvia, Estonia, Egypt, Finland, Belarus, El Salvador, Singapore, Tunisia, Malaysia, Lebanon, Slovakia, Norway, Singapore, Dominican Republic

hypogonadism. In adolescents with PWS, hCG stimulates androgenisation at puberty (increases penis size, deepening of the voice, etc.) but does not rescue spermatogenesis (sperm). (Editor's Note: We now have for sale Dr. Eiholzer's excellent new book on PWS written for parents, *Coping With The Disease – Living With Those Involved*.)

On the Respiratory Issue and Growth Hormone:

- From Japan, researchers reported on two cases of hyperplasia (enlargement or thickening) of tonsils and adenoids after starting growth hormone therapy (GHT). Both showed remarkable improvement in sleep apnea post adenotonsillectomy (after the tonsils and adenoids were removed). (Tomohiro Someya, Chiba City, Japan)
- Another study in Australia reported on six children with PWS on GHT who "developed a significant obstructive respiratory pattern on PSG during growth hormone therapy. This resolved post adenotonsillectomy. No deterioration of underlying central control status was recorded in any patient. (Mark Harris, Brisbane, Australia)
- On the other hand, in a polysomnography of 17 children not on GHT with PWS during a study in Ireland, 82% had abnormalities – four central apnoeas, one obstructive apnoeas, and nine with both central and obstructive. Intervention was required in all children with abnormal studies including adenotonsillectomy and nasal ventilation. (Judith Meehan, Dublin, Ireland)
- And, from Italy, in a study with 18 children who had an overnight cardio-respiratory sleep study done before they started GHT and approximately 16 months after starting GHT, researchers found that nine children (50%) had obstructive sleep apnea (OSA) before starting therapy, and 12 (67%) had OSA during GHT. They stated this does not constitute a significant difference. (Antonino Crino, Rome, Italy)

See Awareness Booth on next page

Blood Draws in Kids With PWS

Individuals with Prader-Willi syndrome may have difficulties with blood draws. The hypotonia and increased subcutaneous fat may make finding landmarks more difficult for the phlebotomist. Dr. James Loker, Pediatric Cardiologist, Medical Director of Bronson Children's Hospital, who is a member of our Clinical Advisory Board, offers the following suggestions that may help.

If your child has had difficulty in the past with blood draws, warn the lab tech that an experienced person will be needed because your child is a "hard stick." The usual guideline is that the phlebotomist should try twice. If he or she is unsuccessful after two tries, then someone else should try. Do not be afraid to ask up front for the most experienced individual. That individual may not be present at the time, so depending on what labs are needed, you might ask if the blood draw can be postponed until that person is present.

In most children's hospitals, the phlebotomist would have the most experience with little children. On occasion the parents might wish to ask for a neonatal nurse to come down for the draw. In smaller hospitals the parents might be able to request a pediatric/newborn nurse, who may have more experience than the phlebotomist, and the hospital may be better able to comply with that request.

Request a prescription from your doctor for EMLA cream to help numb the area. EMLA should be placed on the skin 45 minutes prior to lab draw.

Give your child plenty to drink several hours before the visit to the hospital/doctor. If the weather is cold, bundle them warmly on the way for the blood draw. Ask for warm packs to place on the blood draw site.

**CALL FOR SCIENTIFIC PAPERS
Prader-Willi Syndrome Association (USA)
Annual Conference
July 19, 2006 Scientific Day**

Please submit the following information by April 1, 2006 and submit your abstract by April 15, 2006:

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

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

Your abstract will be limited to one page, single-spaced, with margins of approximately one inch, and a minimum type font size 12. It is our goal to have the abstracts published. Full details, including an example abstract form, are available at the PWSA (USA) website, www.pwsausa.org, and the national office. Notification of acceptance will be provided by May 1, 2006.

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

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

My daughter is REALLY easy to get along with, and quite charming until /unless... a) you ask her TO do something, or b) ask her NOT to do something.
— Anonymous

Awareness Booth - continued from page 6

• Two other studies showed an increase in height and decrease in BMI (body mass index) and that GHT "markedly improves the clinical status and quality of life of most patients with PWS" – but only on condition of compliance and dietary restriction. This is not news to us. In the U.S. we know this from our medical database of over 400 children on growth hormone therapy. We have witnessed over and over the positive effects. **The big questions now are: What is the respiratory risk to our children – with or without GHT? And should we be more aggressive with removing the tonsils and adenoids – especially if they are on GHT?**

Back to the booth: Pam Eisen, Giorgio Fornasier, and I made a great team! It was wonderful to watch Giorgio communicate with people in their own language. He not only knows six languages, he can communicate to a lesser degree in about 10-12 other languages! It was amazing to watch him in action – and the smiles on the physicians' faces when he did speak to them in their own language. We had a good synchronicity going where we would refer to each other as needed and juggle people back and forth.

It was very interesting to see what is going on around the world both on PWS in general and growth hormone specifically. We were told by a physician that China and the Federation of Russia are already using growth hormone for PWS – but drug companies are not interested in them because they do not honor the world trade agreement and make their own, much cheaper version of growth hormone. However, growth hormone companies are interested in Japan because the market there is just beginning to blossom.

Pam and Giorgio were surprised to learn that many more developing countries had a significant amount of physicians working with PWS than they realized and so were able to make some excellent connections for future networking. They were also able to offer those who had no capacity for testing the opportunity for free testing at BIRD, where IPWSO is housed. Due to this offer of testing and all of our free materials, numerous physicians acted as though they had discovered a gold mine. What a wonderful way to help so many people in such a short period of time.



Carolyn Loker with her Valentine, Anna, who has PWS

Be A LOVE

Join Our 4th Annual Valentine Research Fund Campaign

By Carolyn Loker, President PWSA (USA)

What a difference our wonderful families are able to make in their quest of raising money for PWSA (USA) research!

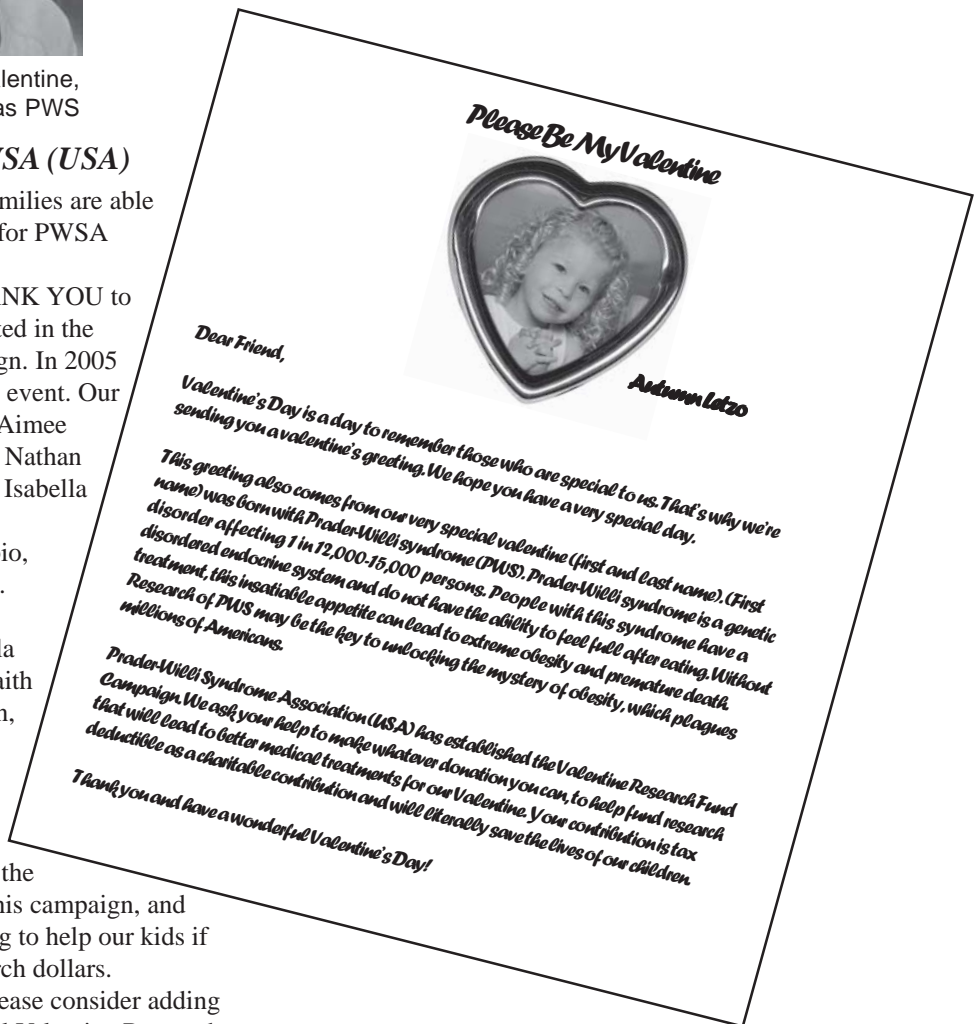
We would like to extend a big THANK YOU to the following 30 families who participated in the Third Valentine Research Fund Campaign. In 2005 nearly \$36,000 was raised by this single event. Our special Valentines were: Alex Agarwal, Aimee Atwood, Rebecca Baird, Oliver Barrett, Nathan Bennett, Sophia Bolander, Nolan Bonk, Isabella Burnham, Melissa Ciaramitaro, Jessika Dickinson, Cody Erickson, Stephen Fabio, Ashley Fender, Cameron Graziano, J. R. Headley, Abby Heathman, Tyler Hess, Connor Heybach, Lexi Higgins, Jo Kayla Howard, Autumn Letzo, Anna Loker, Faith Morse, Jake Pawulak, Roxanne Peterson, Caitlyn Pike, Madison Smith, Leslie Torbert, Brenna Walsh, Sheridan York.

In just three years \$109,000 has been raised as a result of this Valentine Research Campaign. It's exciting to see the research which is being funded due to this campaign, and there are many more researchers wanting to help our kids if we could generously increase our research dollars.

You, too, can make a difference! Please consider adding your special Valentine for our 4th annual Valentine Research Fund Campaign. We make it easy. We will write the letter and include your special Valentine's picture on it — or the letter will be available on www.pwsausa.org in January for you to download and insert a picture of your special Valentine yourself.

We've written the letter so that you can ask your family or friends to send it out as well, to friends, neighbors, family — anyone you feel may want to help.

If you choose, we can do the work for you; just send a picture of your child to the PWSA (USA) office, 5700 Midnight Pass Road, Suite 6, Sarasota, FL 34242, Attention: Diane. Or e-mail the picture to national@pwsausa.org. Tell us how many letters you want and we will scan your picture,



print the letters and send them back to you. Then all you have to do is address them — what could be easier?

Deadline to have your pictures and information to PWSA (USA) is January 27, 2006. Please call Diane at 1-800-926-4797 with any questions. If you would like to make a single donation specifically for research, you may donate on line at www.pwsausa.org or detach the form on page 9 naming your special Valentine and mail to the above address.

If you would like a flyer for your workplace bulletin board, that is available as well by calling Diane at the above number.

Valentine continued on next page

View From the Home Front



A.J. Would Like A Pen Pal

My name is A.J. Larson and I live in Rhinelander Wisconsin. I have two houses, one with my Mom and one with my Dad, I take turns being with them. I am 12 years old and am in my first year of Junior High, its hard and a longer day. My favorite class is art. I love cars and have a lot of them, my favorite ones are the ones that the doors open. I collect buses and the kids for them. I love to go see my Aunt Merlin at her job at the grocery store. She lets me call her Grandma cause my two Grandmas died and I was very sad and miss them very much. I love to be at my Moms cause we go for walks and I get to ride my bike for exersice. I want to be a cop when I grow up, my brother in laws a cop here in Rhinelander. My other sister is going to have three babys, I think thats funny. They have to open her belly to take them out next year. I have two cats at my Moms house, I play cops with them.



Editor's Note: If you are interested in corresponding with A.J., please contact the PWSA (USA) National Office.



A Member of the Wedding

Congratulations to Elizabeth "Libby" Dracup and Robert Fuller, who were married September 25, 2005. Also pictured are Libby's son, Alan King (left) and Libby's daughter, Allison Mahan (right). Allison, 16, who has PWS, was the maid of honor. The bridal couple asked that in lieu of gifts, donations be made to PWSA (USA). Libby and Robert are PWSA members, and have attended many local and national conferences.

The Valentine Research Fund Campaign is our only fund raising appeal dedicated solely to research projects; it is separate from our annual Angel Fund Drive, which also supports essential PWSA (USA) operations and programs. Please help us find treatments to help our children. Many thanks!

Valentine Research Fund Donor Form

Mail to PWSA(USA), 5700 Midnight Pass, Suite 6, Sarasota, FL 34242

My Valentine is _____ My Name is _____

My Address _____ City _____ St _____ Zip _____

Telephone # _____ Donation \$ _____ By Check _____ By Credit Card _____

Credit Card # _____ Exp Date _____

Name on Card _____ Your Signature _____

Make checks payable to PWSA USA. Or donate online at www.pwsausa.org. Click on "Valentine Research Donation." THANK YOU!



Highlights from Scientific Day 2005 National Conference

Part 2 of 2

Sleep in PWS: Sleepiness and Sleep Disordered Breathing- Relationship to Genotype, Growth Hormone Therapy and Body Composition

Korwyn Williams 1, Ann Scheimann 1,2, Vernon Sutton 1, Betsy Hayslett 3, Dan Glaze 1; 1 Depts. of Neurology, Medical Genetics & Pediatrics, Baylor College of Medicine, Houston, TX; 2 Dept. of Pediatrics, Johns Hopkins Univ. School of Medicine, Baltimore, MD; 3 Div. of Pediatric Gastroenterology & Nutrition, Texas Children's Hospital, Houston.

Excessive daytime sleepiness is a common symptom in PWS. Individuals with PWS also have primary abnormal ventilatory responses to hypoxia and hypercapnia; these abnormalities may be exacerbated by obesity.

Methods: Retrospective chart review of all patients followed in the PWS clinic with sleep studies performed at Texas Children's Hospital from January 2000 to present. This study was approved by the IRB at Baylor College of Medicine.

Conclusion: PW patients are at increased risk for sleep-disorder breathing and for excessive daytime sleepiness. Other than lower BMI z-scores, growth-hormone treated patients did not differ from non-treated patients in respect to parameters of sleep-disordered breathing or daytime sleepiness. The presence of significant variability in some of the sleep parameters suggests other factors may play a larger role in sleep-disordered breathing and daytime sleepiness than obesity; further subset analysis and correlation is planned.

Biomarkers for Pediatric Type 2 Diabetes in PWS

Susan M. Sell 1, Renee A. Desmond1, Dongquan Chen1, Chun-Yan Song1, Travis Ptacek1, Andrew B. Crouse1, Theresa Strong1, Douglas C. Bittel2, Merlin G. Butler2; 1 Univ. of Alabama, Birmingham; 2 Children's Mercy Hospitals and Clinics & Univ. of Missouri-Kansas City School of Medicine, Kansas City, MO

As in adults, obesity in children may increase risk for type 2 diabetes (T2D). The incidence of T2D in adolescents has increased by a factor of ten in the past 15 years, according to studies cited by the NIH. A method for determining which obese children are at risk for metabolic complications of obesity is clearly important. A test for biomarkers that requires only a blood draw would be very useful; one easily accessible and renewable cell source is EBV-transformed lymphocytes. We hypothesized that by comparing differential gene expression in subjects with similar childhood obesity histories but different glucose tolerance outcomes, we would identify gene expression biomarkers in children with T2D that would distinguish which obese children are at risk and which are not.

This pilot study provides evidence that results from microarray studies could serve to identify biomarkers for pediatric T2D. Future investigations will explore these endpoints in larger populations.

Psychiatric Resilience among Individuals with PWS and Presumed Maternal Uniparental Disomy Warranting Further Genetic Testing

Linda M. Gourash, Janice L. Forster, Pittsburgh Partnership: Specialists in Prader-Willi Syndrome, Pittsburgh, PA

Individuals with PWS who have presumed maternal uniparental disomy (UPD) have been reported to be at increased risk for bipolar affective disorder or cyclic psychosis. This association has been linked to advancing age (Holland, 2004). We present two middle aged adults with PWS, both carrying the presumed diagnosis of maternal UPD condition and have never experienced psychiatric symptoms apart from those expected for their overall phenotype: Personality Change Secondary to a Medical Condition (PWS).

Despite normal FISH studies performed in 1996 and an abnormal PWS methylation test in 2003, a 46-year-old man presumed to have UPD (or an imprinting defect) underwent genetic retesting with newer FISH studies in 2003. They revealed an apparent atypical small 15q deletion and not UPD.

We present these two case summaries and discuss apparent resilience despite their vulnerabilities which raises questions about establishing the correct genetic subtype diagnosis and retesting older patients. Several mechanisms for resilience are discussed including 1) stress hypothesis; 2) coping hypothesis; and 3) protective factor hypothesis.

Psychiatric Phenomenology of Mood Activation in PWS

Janice Forster, Linda Gourash, Pittsburgh Partnership: Specialists in Prader-Willi Syndrome, Pittsburgh, PA

PWS has been associated with an increased incidence of Bipolar Mood Disorder or cyclic psychosis. This association has been linked to the maternal uniparental disomy condition of PWS, although there are many case reports of individuals with the deletion condition who also display these severe psychiatric problems. Mood activation is an iatrogenic phenomenon associated with the use of medications. It can present with mood elevation, mood lability, irritability, impulsivity or increased goal directed behavior. In neurotypical populations, it has been associated with an underlying risk for bipolar disorder.

The Pittsburgh 100 is a referred population of those with PWS who were admitted for inpatient evaluation and management of medical and behavioral crises who received psychiatric consultation as a part of their treatment. Despite the referral bias of this cohort, the demographics and genetics are comparable to the group with PWS in the general population.

Results and Discussion: Mood activation was predominantly associated with exposure to SSRI medication. Mood activation was not associated with age, family history, hormone replacement or genotype. A history of mood activa-

Continued on next page

tion did not automatically indicate a diagnosis of mood disorder. Bipolar disorder with or without psychosis occurred in 50% of those with mood activation. Other diagnoses occurring in the remaining 50% included anxiety disorder and disruptive behavior disorders. The treatment of mood activation was the discontinuation of the SSRI. The cautious, informed use of SSRI medications is recommended in PWS.

Psychopathologic Disorder in PWS

S. Buono, D. Greco, F. Scannella, P. Occhipinti, L. Ragusa, A. Costanzo, C. Romano; Dept. for Mental Retardation, Oasi Institute (IRCCS), Troina (EN)- ITALY

Data in literature indicate an association between PWS and psychopathological characteristics. Advances in genetics have led to an increased understanding of the role of the genotype on psychological functioning in particular regarding the cognitive and behavioral phenotype.

Our work examines a sample composed of 18 persons with PWS, whose ages range from 2 to 35 years and whose intellectual disability levels vary as follows: slight mental retardation (45%), moderate mental retardation (11%), NOS mental retardation (16%), psychomotor delay (16%), borderline intellectual functioning (6%), normal intellectual functioning (6%). Furthermore, 45% of the persons with PWS examined manifested psychopathological problems. Butler et al. (2004) have reported that the individuals with deletions generally have more behavioral and psychological problems than individuals with UPD. In our sample we have examined the presence of such differences related to these two genetic subtypes. Our study shows that the individuals with deletion have more psychopathological disorders than persons with UPD.

Causes of Death in PWS Utilizing the PWSA (USA) Bereavement Program: Documentation of a Functional Infrastructure

David A. Stevenson¹, Janalee Heinemann², Moris Angulo³, Merlin G. Butler⁴, Jim Loker⁵, Norma Rupe², Ann Scheimann⁶; ¹Div. of Medical Genetics, Univ. of Utah, Salt Lake City; ²Prader-Willi Syndrome Association (USA), Sarasota, FL; ³Dept. of Pediatrics, Winthrop University Hospital, Mineola, NY; ⁴Children's Mercy Hospitals & Clinics & Univ. of Missouri-Kansas City School of Medicine; ⁵Bronson Methodist Hospital, Kalamazoo, MI; ⁶Baylor College of Medicine, Johns Hopkins Hospital, Baltimore, MD

PWS is the most common known genetic cause of life-threatening obesity — yet obesity is not the direct cause of all PWS deaths. Few studies have evaluated the causes of death in PWS, and autopsies are rarely performed. The largest studies of PWS deaths have been documented by Dr. Schrandt-Stumpell, who reported on 27 deaths in PWS, and by Smith et al. at the 2001 PWSA International Conference on 32 PWS deaths from Australia. The report by Smith et al. concluded that death in PWS individuals was occurring at a younger age compared to the general population (56% died between ages 11-25). Another study by Stevenson, et al. documented cases of unexplained death in PWS particularly in infants and children.

Methods: PWSA (USA) has a bereavement program through which cursory data on causes of death have been collected. A committee of various subspecialists was organized, and in 2005 they created a detailed questionnaire. Families have been asked to fill out this new questionnaire and release medical records including autopsy reports.

Results and Discussion: From demographic information on 147 individuals, over 25% died in the first 18 years of life. To date we have received 28 completed questionnaires. Autopsy reports have been received on 12 individuals. This documents a functional infrastructure to systematically collect clinical history information and necropsy data on individuals with PWS. Future results from this study could help delineate causes of death and early demise in PWS patients to provide clinicians with guidance in patient management to decrease morbidity and mortality. Identification of preventive measures and education (e.g. Heimlich maneuver if choking is a major contributor) may be of some benefit.

Necdin and MAGEL2: Candidate Genes for PWS

Rachel Wevrick, Jason R. Bush, Megan A. O'Neill, Alysa A. Tennese, Sharee L. Kuny, Christine L. Walker; Dept. of Medical Genetics, Univ. of Alberta, Edmonton, Canada

The necdin and MAGEL2 genes are both inactivated in PWS, along with two other protein-coding genes (SNURF/SNRPN and MKRN3) and a gene for a set of regulatory RNAs (IC RNA and snoRNAs). Necdin and MAGEL2 are highly related proteins that share a conserved 189 amino acid MAGE homology domain. To determine the etiology of PWS, it is critically important to understand the role of necdin and MAGEL2 deficiency in humans, and to correlate findings in necdin-null and Magel2-null mice with the clinical and pathological findings in PWS.

Our experiments address the biochemical, cellular, and developmental roles of necdin and MAGEL2, as they relate to loss of gene function in PWS. In summary, our studies examine the contribution of loss of necdin and MAGEL2 function to the complex neurobehavioral outcomes in individuals with PWS.

Research in the Wevrick laboratory is supported by the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada, and the Alberta Heritage Foundation for Medical Research.

A complete listing of Abstracts from the PWSA (USA) 2005 Scientific Conference is available in the Members Only section on the website, www.pwsausa.org, or can be obtained by calling the National Office to request a copy.

Members Only Features Dental Care Tips

R.N. Barb Dorn (parent of Tony, who has PWS) and Orthodontist Tom Hughes (parent of Sara, who has PWS) of the PWSA Wisconsin Chapter have written an article about dental care for those with the syndrome, including Ask the Dentist, brushing and flossing, preventative care, insurance issues, and finding a dentist.

It's available in the Members Only section of our website, www.pwsausa.org



Now **ON SALE!** Our 2006 PWSA (USA) Calendars

Each month features color photos of lots and lots of our kids!
They make great holiday gifts, or use them for fund-raisers.

Prices now reduced to \$10.00 each, three for \$25, seven for \$50, and includes shipping. Buy a box of 65 calendars at a cost of only \$5 each, no shipping charges either!

Order your 2006 calendars NOW while supplies last. Call PWSA (USA) at 800-926-4797 or 941-312-0400; fax to 941-312-0142 or e-mail national@pwsausa.org.

Sugar Plums - continued from page 1

with PWS. To help mom, let each person take an hour, and clearly define when you are changing guards. As Dr. Linda Gourash says, "When everyone is in charge — no one is in charge." Grandparents or another relative may want to bring a special gift toy to compensate for food they have to deny your child.

No matter your child's age, it is important to talk with the hostess about limiting the accessibility of food. See that there will not be bowls of food, rolls, or condiments near where your child is sitting. Why put temptation in their way? Afterwards, when people are just visiting, if the food cannot all be put away, see that it is in one location with someone responsible for guarding it.

If you had an agreement with your child, and he/she decides to push the issue, be prepared for one of you to leave with the child rather than giving in to avoid a public scene. Your child must have the security of knowing you will be strong in your commitment to keep them protected from food — in spite of themselves. This is different from keeping your negotiated agreement made ahead of time. Giving in, even

once, means several battles ahead. Consistency is the key.

Christmas or Hanukkah — These are often a longer challenge due to the excitement of visitors, changes in schedules, holiday treats, parties with plentiful food, and gifts of food. Our PWS families are *not* the ones decorating their trees with strings of popcorn or cranberries, but they may be visiting homes that have food temptations all around. You may want to call ahead and alert the hostess about your concerns, and agree where and when food items will be accessible. It is okay to ask Grandma and other relatives to tuck away tempting items during your visit and to discreetly ask you prior to offering your child a treat.

Of course, each family must judge their own situation based on their child's food drive and their own regulations on treats. Some families are raising their children to never have sweets — no exceptions. Others (like ours) go by calories and the child's weight, trying to keep the diet less in quantity, yet similar to others in variety. Often the most important thing is preventing food sneaking or food demands. Food drive varies greatly in children with PWS. Some will ask or beg for more food, but make no significant attempts to sneak food. Others will go to great extremes to get food and are incredibly clever at doing so.

One parent I know has an adult daughter with PWS who is just over four feet tall and considered very low functioning. One Christmas when she was a teen, her parents wrapped gifts, including sealed boxes of candy for the dad's staff. Intermingled with other gifts, the candy was put on the high shelf in the closet in a locked room. The next morning, they found that their daughter had managed to pick the lock, stacked items on a chair to get to the gifts, and had unwrapped (and eaten, of course) only the boxes of candy. How did she know anything was there and which gifts were the candy? We are often puzzled by the gifted skills at acquiring food of our children who are more food driven.

Remember, it is also your holiday — take special time away from your children. Tell your relatives what you would like for a gift is a day, night, or weekend away. Then you can come back refreshed to help make it a happy holiday for all.

The Chuckle Corner

Just Say No!

My 6-year-old son and I recently attended a Stranger Danger course taught by a local police officer. On the way home I quizzed and role played various scenarios to see what he remembered.

When asked what he would do if approached by a stranger in a car who called, "Come here, little boy, and I'll give you a piece of candy," instead of the correct response, "No!" followed by his running

away in the opposite direction, Cameron replied ever so politely, "No thank you. My mommy only lets me eat healthy food."

Seems we need a bit more practice.

Lisa Graziano
Redondo Beach, California



Sibling View

Dawn Cared For Others With Patience, Love and Kindness

By Sharyl Ramos, the Middle Sister

My sister Dawn Ficarro was born November 19th, 1962. We were only 22 months apart. As we grew, you knew that we were quite different. As a child I didn't pay much attention, but adults would always say that Dawn and I did not look like sisters and that would make me mad. You see, she had blond hair and blue eyes and very pink in skin tone, and my siblings and I are olive skin and brown eyes.

She was such a sweet girl. I remember that as a small child she hardly got sick. Whereas myself, I would get sick almost every year. Of course, sweet girl that she was, she would care for me like a mother hen. I would tell her that she should be a nurse because she took good care of people.

All through her short life she cared for people. The hard thing about my sister having PWS was that it was not diagnosed until she was 38 years old. When I dealt with her symptoms of the disease, I dealt with it as if she was normal. She was very high functioning and her weight did not get so bad until adulthood.

When we were young, the only time we actually fought was when I tried to change our bedroom around, and now I know that this is a difficult thing for PWS people. We used to play for hours in our swimming pool. We would also play dolls, house, doctor, and school (of course she was the teacher, mother, doctor).

But the sad part comes when I started to actually live these things, and she wanted to still play. When we went to school together, our friends were totally different. We never really hung around together in high school although she had a good time in school. I remember her arguing with my mom and dad about homework, not that she would not do it, but it had to be a certain way. Just so. She was very passionate about her work; because of that she was able to graduate from high school and to go on to earn an A.A. in Early Childhood Development.



Dawn Lucia-Ficarro (left), who had PWS, with her sisters Christine and Sharyl

We had a coming together, so to speak, when I got married and had children. By this time we knew she could not bear

children so I told her that my children were hers, too. She cared for them so well, just like she took care of me with love, patience and kindness. She would make them toys, books, draw pictures, and read to them. She also taught them to swim. They are both excellent swimmers to this day.

Looking back, my sister had a good life; she brought love and joy to many people. Although it was a much too short life. She was able to marry, have her own apartment, and a short part-time job. She did child care up until she was not able to care for herself. Boy, she missed that! Whenever there was a baby near by you could find Dawn playing with and feeding the baby. I think that makes me really sad that she never had the joy of having her own child.

In retrospect, my sister taught me a lot about perseverance; she never gave up on anything, right or wrong. How she would fight when she got sick with a cold, diabetes, or even heart failure. She never gave up until her body could not take it any more. She wanted to take hormone replacement, but by the time we found out that she had PWS she was too overweight to take it.

I miss my baby sister and I think I will never stop missing her until I see her again.

Members Only on the PWSA Website

Be sure you get into the habit of visiting the **Members Only** section, which will become increasingly important.

Many new items are now in this area, and more will continue to be added: research abstracts from the 2004 Scientific meeting, 2004 IPWSO abstracts, preview of the new homepage prior to being published on the main site, handouts and brochures, current news on PWS, research abstracts from the web, and a new thing like eBay where you can put new or almost new items for sale.

A planned "Ratings" column will warn viewers about its content (like the movies). A "Q" rating means "Recommended for parents of teens and adults." A "Q + 6" will mean "Recommended for parents of children age 6 and up."

You must be a member of PWSA (USA) to enter that section of the site. Password and Usernames are in *The Gathered View* on page 2 and are changed periodically.

Surveys and Commentary Sought for Sibling Booklet

Thanks to all who have done the sibling survey or sent an essay about their brother or sister with PWS for the sibling booklet! **The deadline has been extended to December 31, 2005**, so if you haven't already, there is still time for you to email an essay to ssurvey@pwsausa.org or snail mail it to the national office. You can fill out the sibling survey online at www.pwsausa.org/sibling.asp or ask for a copy from the national office. All contributions for the sibling booklet are welcome!

— Lota Mitchell, Associate Editor

We Remember...

Every person has something special to offer this world — and we, along with their families, want to share who they were and what they meant to the people who loved them.

Jonathan Ross Davis



Jonathan Ross Davis, 22, died of obesity-related complications on February 21, 2005. Born August 30, 1982 to Charlie Davis III and Elisabeth Luna in Dallas, Texas, Jonathan is also survived by brothers Charlie T. and Michael, grandmothers Dorothy T. Davis and Maria T. Luna.

His father wrote that Jon had a place in his heart for all people and loved all animals. He loved to watch movies, play video games, and followed his sports team, the

Texas Rangers, with a passion. Jon enjoyed fishing and camping with his dad (pictured above), going to softball games or just hanging out. “He would talk his mom’s ear off. There was no one as unique as Jonathan. He is loved and he gave his love. We will miss him dearly but he will live in our hearts forever,” wrote his dad.

Phillip Howell



Phil died August 13, 2005 at the age of 33 of obesity-related complications, including sepsis following cellulitis in his right leg. His mother Carole wrote that Phil had suffered bouts of cellulitis a number of times, and wants to alert parents of how serious the condition can be.

Carole said Phil loved his sisters and all the grandbabies. “Phil was the center of our world and facing life without him is unbearable. He told me every day that I was the best mother he ever had.”

Phil loved church and he loved to sing. Phil also loved to write letters, and his mother has an album with copies of letters he wrote to everyone from Billy Graham to the cast of “All My Children” and all of the presidents. He loved Christmas, and always wrote his letter to Santa in October so Santa would be sure to get it.

Born in 1972, Phil was not diagnosed with PWS until he was 16. He struggled with weight, diabetes, high blood pressure, high cholesterol, blood clots in his legs and lungs. Through it all, his mother wrote, “Phil was always the best patient and never complained, no matter what happened. I treasure every day I had with Phil. He was a blessing in our lives.”

The PWSA (USA) Bereavement Program is coordinated by volunteer Norma Rupe. We offer free bereavement support materials for our members, along with envelopes for memorial donations. For more information about these and other materials, please contact the PWSA (USA) National Office.

Sorrow and Praise

Dear Norma, I am very saddened to learn of Jon’s death, but it is refreshing to know that today’s research is blazing a trail for men, women, and children who suffer from PWS. I am very grateful for people like you who pour countless hours of their lives into a cause that provides hope for tomorrow for so many. Life is so precious, so valuable, and this family expressed just how valuable Jonathan was to them. I hope you can continue to share the hope of tomorrow and the value of life with families around the world. You and everyone at PWSA(USA) are doing an amazing work, a work that would put you amongst the ranks of a hero. God bless you.



Wild Willy

Derek Snitker (Wild Willy)

Editor’s Note: Wild Willy was a popular character with the YAP Group at this summer’s National Conference.

Document, Document, Document!

What is as important for your child with Prader-Willi syndrome as a birth certificate? A copy of the diagnostic test confirming PWS. In the on-going survey which PWSA (USA) is currently collecting, 23% birth to five, 24% age 6 to 18 and 51% over age 18 do not know what sub-type of PWS their child has. Parents/guardians have a right to request copies of the child’s medical records.

In the Members Only section of our website, www.pwsausa.org, you can find forms to download so that you can create your child’s Care Notebook. The forms include weight/height charts, doctor visits, lab work, medications record, and much more. These Notebooks can be a life saver in an emergency situation. Take some time today to create a Care Notebook — you will be glad that you did.



Contributions In Memory Of

Celeste Baar Thomas & Agnes Hughes	Larry DeYoung (cont'd) Alice Marilyn Crane Louis & Dawn Haverlock Basl Virginia Miner Fai & Nancy Gonzales, Jr. Betty Lou Mitchell Theresa Reeves Stanley & Priscilla Antonowich, Sr. Florence & Donald Smith Thomas & Eleanor Spellman John & Hope Eisentrager Agnes & Mary Jane Searles Nancy Hogan Fordy & Jerrie Parsons Mr. & Mrs. Emery Malasits Carolyn Veilleux Madeline Tesseo Heather & Stephen Burnham Jr. Michael & Nancy Leahy Marion & Milton Wheaton Margaret Simpson Bar Harbor Police Fund	Mary Angela Risch Halter (cont'd) Charles & Deborah Hentz Mary Tieken & Anne Armbruster Walter & Nancy Deckard, Jr. Randal & Sharon Overbey Richard & Mary Faulkner Joseph & Julia Oblon David & Lauralee Dziennik Michael & Kathy McCarthy Richard & Janice Stanely Mark & Cheryl Wolfschlag Andrew & Suzanne Smock Robert & Kelli Kappus James & Joan Bartley Michael & Kellie Hammans James & Janice Schwartz Frederick & Candace Young Paul & Patricia Ruth Basil & Hilda Woodfork Larry & Mary Lou Clark Bonnie Larosa Therese Maxwell Mark & Cheryl Wolfschlag Linda Tromley David & Judith Curtis Theresa Frye Doris Hurm Robert & Linda Gaither Janet Huck Chris & Nancy Hepp Earnest & Gayle Bledsoe Louis & Julia Feagans Angelia Doane David & Catherine Loudenback Todd & Jill Wagner Randolph & Rebecca Morgan Philip & Amy Montefalco David & Judith Clark Steven Anderson Don & Teri Margason, Jr. Donitta & Kevin Barrer Donald & Ruby Meacham James & Mary Risch Richard & Loretta Utterback Eli Lilly Federal Credit Union Daun & Darryl Simpson Thomas & Suzanne Halloran, Jr. Mark & Julee Jacob Nancy Slye Judith Ann Duesterberg & Barbara Acker	Mary Angela Risch Halter (cont'd) Richard White Robert & Mary Ritz A&A Industrial Supply, Inc. Joseph & Amy Kuntz Susan Rene' Ross William & Frances Rajk William & Martha Kuntz Tim & Geri Fey Jennifer & Daniel Quinn Michael & Jackquelyn Clements John & Kathleen Spotts Andrew & Diana Roessler Michael & Mary Brown Herb Kirchoff Charles & Dorothy Ringstrand Carole & Scott Ringstrand Mr. & Mrs. William Kirchoff Barbara Miller LaFebvre Lota & Dave Mitchell Mark Lesti Mr. and Mrs. Carl Schauer Donald and Beverly Erickson Peter Meyer Carolyn Meyer Lawton Miller Harold Cousar Cynthia Poston H. Edgar Anderson Janet Wallace Moore Steve & Theresa Baloga Gerald Mouser Anonymous Myrna Reynolds Myrna Reynolds (relative) Johanna Newton Lorryn Tomasicchio Kathleen Ranberg Chuck Ranberg Andrew Rico Friends of Jerry Alexander Bob Rutherford Janice and Richard Trujillo Judy Whittlesey Frederick & Carol McKeehan Pieter Jan Brugge & Anna Boorstin Jean Witherow Ann Brunner Henry Steinway & Aline Smithson
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A Note To Our Readers

Because of production problems, some members did not receive the PWSA (USA) Annual Report for 2004 with last month's issue of *The Gathered View*. The Annual Report is available on our website, www.pwsausa.org, or you call the national office to request a copy.

Issues of *The Gathered View* will henceforth list only Major Benefactors and contributions in Memory Of and In Honor Of because of space limitations. All other donations, including those to the Angel Fund and Valentine Research Fund, will be listed in our Annual Report for 2005. This allows more space for medical information and articles.

As always, we sincerely appreciate the generosity of those who help support our mission to enhance the lives of everyone impacted with Prader-Willi syndrome.

PWSA(USA) gratefully acknowledges the printing and mailing of our newsletter is made possible by a generous grant from CIBC World Markets Corp./Miracle Day USA, helping children around the world

Contributions

Thank you for Contributions through September 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.

