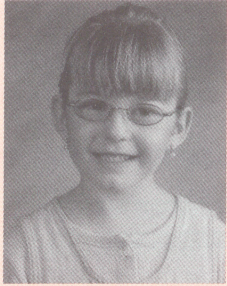




March-April 2007
Volume 32, Number 2
Our 32nd Year of Publication

The *Gathered View*

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



Ashley Fender, Illinois

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Donations for Research
Net through 12/ 31/ 2006:
\$226,950
As of 1/31/07: **\$19,320**

A High Achiever By Any Standard

By Lota Mitchell, Associate Editor

Penny Townsend is one proud mom! In October 2006 she accompanied daughter Beth, 31, to San Diego where Beth received The Arc US Bill Sackter Award. This national award recognizes an outstanding individual with cognitive, intellectual or developmental disabilities who is an achieving member of society.

A resident of Albemarle, North Carolina, who wasn't diagnosed with PWS until she was 8 years old, Beth had first won the local Arc of Stanly County award and then was nominated for the national one. To accept the award, Beth had to give a speech in front of several hundred people. She and Penny worked on writing it together, and Beth practiced hard in preparation.

Beth has owned and operated a business called Celebration Gallery since 2003, which sells such items as figurines, pocketbooks which look like high-end purses and sell like hotcakes, jewelry, and designer replica sunglasses. The sunglasses she also places in a couple of local tanning salons in a middle-man capacity.

When she first began working at The Arc of Stanly County workshop, she was bored. She tried other jobs, like working in a veterinarian's office, a greenhouse and a childcare center. Finally she identified what she really liked — shopping, making things, and being with people. Starting out at first making personalized gift baskets, she moved into selling small retail items. Then she began making crafts and buying items wholesale, then going out into the community to sell them. Beth had found her real love! So now she is busy buying wholesale and selling retail. She does most of her own bookkeeping under supervision of her staff person, Cherie Efird, and figures up her own taxes on her sales. She uses a portion of a large Arc workshop for her shop, where people can come in and shop or

Beth Townsend, who has PWS,
operates her own
specialty retail business



can call for what they want. A nice profit was made over Valentine's Day selling stuffed bears and balloons, plus delivery fees.

In addition to her shop, Beth has purchased a big tent for open-air market events and displays her wares at local fairs and parades. She still creates made-to-order gift baskets for holidays and special occasions, designed to please both her customers' purses and preferences. Besides running and managing her own business, she also serves on several clubs and committees, making her an integral and well-known part of her community.

Beth continued on page 12

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* is not a substitute for individual care by a licensed medical professional.

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Deadlines to submit items to

The Gathered View are:

December 1; February 1; April 1; June 1;
August 1; October 1

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 impacted by Prader-Willi syndrome.

Members Only: Check our website www.pwsausa.org for downloadable publications, current news, current research and much, much more limited to members only!

User Name: pwsamember Password this issue: texas07

Note: If you have difficulty logging in to the site, you may be using a browser that prevents you from entering authenticated websites. Try minimizing your program (e.g. AOL) and clicking on Internet Explorer or Netscape. Then type in the URL: <http://www.pwsausa.org/memberonly.htm>

E-mail Support Groups: We sponsor seven e-mail support groups to share information. You'll find them listed on the web at <http://www.pwsausa.org/support>

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Update on Three New PWSA (USA) Research Grants

Abstracted By Jamie Bassel, D.C., PWSA (USA) Research Committee

Effect of Rimonabant, a new anti-obesity medication, on appetite, feeding behavior, body weight, and composition of Patients with PWS

*Roja Motaghedi and Moris Angulo**

Rimonabant (acomplia) works by blocking the CB-1 receptors that manages food intake. The receptors are in the brain, but also throughout the body, particularly in fat cells. Among other things, they account for the abrupt increase in appetite experienced by people who smoke marijuana.

Doctors claim that this system of receptors is disrupted by chronic overeating. The drug re-establishes the balance in the system, repressing appetite.

Acomplia's unique of approach attacks the receptor in the brain that makes people hungry when they smoke marijuana. This protein receptor is referred to as the cannabinoid receptor found on the surface of brain cells.

Researchers in Europe have demonstrated that obese patients treated for 1 year on the dose of 20 mg per day lost an average of 19 pounds and 3.5 inches of waistline, while 39 % lost more than 1/10th of body weight. The drug also elevated levels of "good" HDL blood cholesterol by 27 %.

This medication is undergoing FDA investigation and has not yet been approved for use in the U.S. Researchers will be examining its use with individuals with PWS to determine its effects on weight loss, ghrelin and leptin levels. The study will also examine Rimonabant's effect on appetite and feeding behavior in individuals with PWS.

Expression of 4 genes between chromosome 15 breakpoints BP1 and BP2 in subjects with PWS and impact on cognitive and behavioral measures

*Douglas C. Bittel, Jennifer Zarcone and Merlin G. Butler***

There are two distinct typical chromosome 15q deletion subtypes (type I and type II) in PWS. The larger type I (TI) typical deletion includes breakpoints BP1 and BP3 while the smaller type II (TII) typical deletion includes breakpoints BP2 and BP3. The effects of the two distinct deletion subtypes on clinical presentation are under investigation.

Four genes have been recognized between BP1 and BP2 and include *NIPA1*, *NIPA2*, *CYFIP1* and *GCP5*. It has been reported that these deleted genes may impact on cognition, behavior and visual integration, with poorer scores reported in those PWS individuals having the larger TI deletion. Specifically, the most striking observation is the significant correlation of *NIPA2* gene expression with adaptive behavior, academic achievement, and visual motor integration scores along with obsessive compulsive behaviors in PWS.

The purpose of this study is to better comprehend the importance of the four genes located between breakpoints BP1 and BP2 through gene expression studies and to better quantify the differences between the genetic subtypes. A greater exploration into the contribution of these genes and their effect on cognition, behavior and neurological function

along with the genetic subtypes of PWS will aid in a better understanding of the pathophysiology in PWS leading to treatment modalities.

Gonadal Function in Infants, Adolescents and Young Adults with PWS

Harry J. Hirsch and Varda Gross-Tsur, The Multidisciplinary Clinic for Patients with Prader-Willi Syndrome, Neuropediatric Unit, Shaare Zedek Medical Center, Jerusalem, Israel

Hypogonadism is considered to be a consistent finding in all individuals with Prader-Willi syndrome. Nearly all male infants with PWS have micropenis and/or undescended testes). Pubertal development in both sexes is usually delayed and incomplete. Although girls often have significant breast development, spontaneous menstrual periods are uncommon. Pregnancy has been reported in a few women with PWS, but there are no reports of fertility in men. Hypogonadism results not only in immature appearance and behavior, but increases the risk of osteoporosis.

Recent studies have challenged the concept that hypogonadism results only from a central hypothalamic-pituitary gland defect. Longitudinal studies in a small number of male infants with PWS suggested that they may have a primary testicular defect with normal pituitary gland responses.

In the Israel patient population, observations are that reproductive hormone levels are variable, and some people have sex hormone levels within the normal range for age. In addition, some adolescent and young-adult PWS patients are interested in dating and other age-appropriate sexual activities. These observations suggest that the degree and expression of hypogonadism in PWS is more variable and less consistent than has been previously reported.

Researchers plan to measure pituitary gonadotropins and gonadal hormones across the age spectrum. They will interview older adolescents and adult patients regarding sexual interests and behavior. The findings should help determine relative contributions of gonadal vs. central (hypo-thalamic-pituitary) dysfunction in explaining hypogonadism in PWS. Assessment of sexual interests and behavior will provide information regarding normative behavior which will be important for families and supportive living caretakers.

**Moris Angulo, M.D., Winthrop University Hospital, Mineola, New York, is a member of the PWSA (USA) Clinical Advisory Board.*

***Merlin G. Butler, M.D., Ph.D., Children's Mercy Hospital, Kansas City, Missouri, chairs the PWSA (USA) Scientific Advisory Board.*

CLARIFICATION

In our Jan-Feb 2007 issue we reported on Alex Ashe's successful weight loss at The Children's Institute. However, the article should have noted that Alex entered weighing 233 lbs. and left 8 weeks later weighing 197.7 lbs. He continues losing weight and is now 133 lbs.



Executive Director's View

Now Available: After Hours Medical Crises Support

Janalee Heinemann

Thanks to Colleen's Angels, we now have an after-hours support person available when the PWSA (USA) office is closed. This person, Prentice Lantzer, will be able to e-mail or fax needed information to emergency rooms and hospitals. In extreme emergencies, she may be able to provide a physician-to-physician consult.

This service is a pilot project that will be for medical emergencies and deaths only. The number is 941-993-7638. This number will also be available on the office voice mail. The decision to continue this program beyond a year will depend on funding and an evaluation of the need.

I have dreamed about having this service for some time since I cover most of the medical crises, but it is thanks to Bill and Connie Devitt and their Irish American community that this dream has come true. They organized a fundraiser in memory of Connie's sister Colleen Doherty. Colleen had PWS and died at age 39 from a bowel obstruction two years ago during the holidays. Their hope is that Colleen's memory lives on through the support that will be provided for others.

We have already received the following positive feedback:

- *"I think this is an incredible resource. We seem to never have any emergencies during the day of course and in these situations we are always faced with dealing with a Dr. and staff that knows nothing about PWS or our child. (Like the ER Dr. that told us Ethan's chest X-ray looked "fluffy" and wanted to send us home?) It's wonderful to have some support available when we need it most!"*

PWS Awareness Brings Increase in Crisis Cases

2000	231
2001	391
2002	352
2003	496
2004	470
2005	483
2006	730

- *"WOW Great! I've been to the ER with Luke about seven times or more with sometimes nothing —thank God — but other times seizures from surgery. This is such a needed service. Thanks so much."*
- *"This a wonderful service and is so needed. I would love to thank Colleen's family. Thanks for all you do for us also."*

- *"Thank you so much for this pilot program starting. We all never know when an emergency will arise. Believe me, I have already had to call poison control and 911...and he's only 3 years old. Thanks again for all you do for us."*

We PWSA (USA) staff, officers and board members have the most intimate knowledge of the needs of our children and their support people, but it is thanks to volunteer fundraisers like Colleen's Angels that we can put the vision and resources together to make the impossible possible. As Margaret Mead once said: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has."

Together we are changing the world of Prader-Willi syndrome. Colleen made a difference in her life — and she continues to make a difference even after her death. I know she is smiling down on us and looking over all of our children.

More About Colleen's Angels

Bill and Connie Devitt and their Irish American Community organized Colleen's Angels for PWS in memory of Connie's sister Colleen Doherty.

Their cocktails, dance and silent auction raised \$20,780 for the crisis hotline and research, plus funds for the Prader Willi Association of Wisconsin. (Wisconsin is where Colleen lived.)

Their hope is that Colleen's memory lives on through the support that will be provided for others.

"What stood out for us more than anything..." Bill wrote, "now there are at least 500 more people that are aware of Prader Willi." He was pleased to meet other PWS families and impressed by the amount of support the fundraising effort received, including the Irish American community and his personal physician, who wants to learn more about PWS. "We never could have gotten the results we did without the help of so many friends.... My mother wanted me to know that it is much better to give than receive," Bill added, "and I can't tell you how wonderful I feel knowing that."



Colleen Doherty

Research View

Participants Needed for Two Surveys of People with Developmental Disabilities

The George Jervis Clinic at the New York State Institute for Basic Research in Developmental Disabilities on Staten Island, New York, is conducting two surveys for people with developmental disabilities. Paul Patti, M.A. Research Scientist and Maureen Gavin, RN, C/ CDDN are principal investigators for this project.

The Gastrointestinal Symptoms Survey is designed to determine the presence or absence of common gastrointestinal (GI) symptoms in children and adults with developmental disabilities. GI complaints are especially common among people with PWS and Down syndrome but also occur with other disabilities. Symptoms or complaints can occur at any age, and range from mild to severe. Specific symptoms can affect digestion and the absorption of vital nutrients. The survey may help identify unrecognized GI problems to be evaluated by a health professional.

The Self-Talk Survey will study the prevalence and style of "self-talk," which is important in developing higher-level thinking and self-direction. By age 7, most children develop an internal dialogue when working out problems or challenging tasks. This may be different for people with developmental disabilities. Talking out loud may allow them to work out difficult situations, express feelings and entertain themselves. Although self-talk is reported as common in Down syndrome, no studies have looked at self-talk in children or adults with PWS or other developmental

disabilities. Studying this behavior may help better understand a person's emotional state of mind.

Parents and family of children and adults with PWS are asked to complete both surveys. Participation is voluntary and information provided is confidential. If interested, contact Paul Patti by telephone 718-494-5315, fax 718-494-2258 or e-mail paul.patti@omr.state.ny.us. For more information, write to Paul Patti, M.A. at the George Jervis Clinic, Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Road, Staten Island, New York 10314-6399.

New Column To Begin: Ask The Advisory Board



In our ongoing effort to provide support for children and adults with PWS, we will begin a column where readers can ask advice from our PWS Advisory Board members. Pictured above L-R (back row): Andy Maurer, Abbott Philson, Conor Heybach; (front row): Shawn Cooper, Brooke Fuller, Kate Kane. Not pictured is Margaret Miller.

If you are a person with PWS or you have a child with PWS, you are invited to send your questions to:

Prader-Willi Syndrome Advisory Board
c/o PWSA (USA)
5700 Midnight Pass Road
Sarasota, FL 34242

If you cannot submit your question by writing, call and tell us your question at 1-800-926-4797 during working days (Mon.-Fri. between 9:00 a.m. and 7:00 p.m. Eastern time). We will keep your name confidential.

Henoch Appointed PWSA Parent Delegate to IPWSO

PWSA (USA) is pleased to announce Susan Henoch as parent delegate to IPWSO, the International Prader-Willi Syndrome Organization. She and husband Jay Coggeshall are parents of Sophie, a 19-year-old young woman with PWS.

Susan brings extensive experience with educational and administrative issues as well as a long-term involvement with national and international outreach and support. She is excited to assume her duties and responsibilities on behalf of PWSA (USA) and we are proud to be so well represented.

PWSA(USA) gratefully acknowledges the production, printing and mailing of our newsletter is made possible by a generous grant from **Pfizer**



President's View

Imagine Life Without PWSA (USA)

Carolyn Loker

I can't even begin to imagine what Anna's "world" and my family's life would be like without PWSA (USA). Reflecting back to the year of her diagnosis in 1996, when she was 18 months old, we were devastated, shocked and in disbelief that our precious little angel would have to endure the vast array of possible complications involved with this disorder. After extensive reading, I saw no positives, no light at the end of a dark tunnel.

I needed someone to say "It's really going to be okay, we have parent mentors who will help you through this process. And by the way, there is growth hormone and don't forget to check thyroid levels. Oh, and if you have any questions about medical issues, just call the PWSA (USA) office, we can find out the answer for you because we have PWS expert doctors who will help."

And I needed someone to tell me "If you have a medical crisis, make sure you call the PWSA (USA) office and if the office is closed, you can still call because we have an after-hours medical crisis line, and if you have any other kind of crisis, we have excellent crisis counselors who can assist you."

Instead, all I could do was cry and imagine a life without hope for our precious daughter until we found out that PWSA (USA) existed.

It was a very small organization at that time, housing a part-time secretary and an executive director. I called and the nice lady told me to

Growth of PWSA (USA) Young Parent Mentoring Program

	2000	2006
YPMP I:	15	143
YPMP II:	1	36

My dream was to support other parents so they would hear more than just "I'm sorry." This is how the parent mentoring program was initiated seven years ago.

call my chapter and maybe they could help. Then I was put in touch with another family, hoping that I would hear "It's really going to be okay." Instead I heard the voice on the other end of the phone saying "I'm sorry."

Five months later we mustered up the courage to go to our first national conference. A little glimmer of hope began to surface and I didn't feel so all alone. A few weeks later I decided that I could either try to help change things by being involved with PWSA (USA) or live with my head in the sand. Fortunately, I decided to become active in PWSA (USA) and it changed my life.

My dream was to support other parents so they would hear more than just "I'm sorry." This is how the parent mentoring program was initiated seven years ago. Thanks to the PWSA (USA) staff and 65 parent mentors across the country, we have now served more than 900 families with infants and toddlers who have PWS since the program began.

I would like to express my gratitude to all the parents who came before me. For it was their vision to create and sustain PWSA (USA). Without these pioneering families, there would be no PWSA (USA), and I cannot imagine our family's life without the support of other PWS families throughout the country and the world.

Hugs.

May is PWS Awareness Month 2007

May is PWS Awareness Month, a public education initiative first launched by PWSA (USA) in 1993. We're pleased to report that last year's PWS Awareness Month Spokesman Clint Hurdle has agreed to be spokesman for 2007 as well.

Help Clint raise awareness by activating a chain reaction of PWS knowledge in your community and elsewhere! Plan a fundraiser, contact media and political representatives and conduct PWS education trainings at your child's school or with his/her health care team to enlighten others about PWS. The possibilities are endless with your imagination and effort.



Visit the awareness section of the PWSA (USA) website, www.pwsausa.org, for ideas and tools you can use to make a difference.

If you're planning a fundraiser, please remember to register it to be posted on the PWSA (USA) website at www.pwsausa.org/fundraising/activityform.htm.

Call the PWSA (USA) office at 800-926-4797 or 941-312-0400 to let us know about your undertaking and be prepared to reach your own state of awareness when you realize the satisfaction of making the world a better place for our loved ones who have PWS.

— Jodi O'Sullivan, Community Development Director



Locks and Alarms: Food Security for Those With PWS

Prepared by Barb Dorn, R.N., B.S.N., Crisis Intervention Counselor, PWSA (USA)

To keep a child or adult with PWS safe and secure, parents and care givers must use locks and/or alarms to prevent him/her from accessing food. Although this may seem cruel, it is life saving. Locks and alarms are safety measures. They improve the quality of life for those with PWS as well as those who support them. Locks and/or alarms can:

- Prevent binge eating, which could result in death.
- Prevent extraordinary weight gain which results in morbid obesity and many medical complications.
- Prevent anxiety and guilt over being able to seek out and eat food they know they should not have.
- Allow those who support them to sleep and do other activities that may distract them from the need for constant surveillance of food sources.

How Will We Know When It Is Time To Apply Locks?

There is no specific age or pre-determined time that locks are applied. Some may need to apply them when the child is very young; others may not need to do this until the person is older. Indications that the time is near or now include:

- You see an increased preoccupation with food with more observable food-seeking behavior.
- You may also see an unexplainable weight gain.
- You discover that food is missing.
- The person with PWS may tell you that she/he is taking food.

Once locks are applied, many with PWS report feeling “safer” because the burden of temptation and guilt is removed. Locks are often more difficult for parents and family members than for the person with PWS.

Initially if the younger child has fine-motor weaknesses, child-safety locks may be enough. Once the weaknesses become less, you will need to apply stronger, more secure locks.

Often parents report that they “just knew” it was time.

Keep Food Out of Sight

Keeping food out of sight is a common, courteous practice that most parents and care givers do – no matter what degree of intensity exists in the person’s food drive. Having food out of sight may provide less temptation, thus preventing the person from experiencing anxiety, guilt and failure. When people leave food out, the person with PWS is less able to focus on other activities; she/he is being set up for failure. Any steps that can help with this challenge must be taken.

Which Way is Best?

When it becomes time to apply locks and/or alarms, there are many methods to secure food. For example, some families have locked up kitchen cabinets, some have built pantries into broom closets, many have padlocked refrigerators (twin padlocks with the same combination can be found, thus avoiding having to learn more than one combination).

There is no one right way — any way that helps the person with PWS to be safe and prevents food access is the best and correct one.

Resources

To view this article in full with detailed pictures and information on locks and alarms, visit our web site, www.pwsausa.org, then go to Publications-Members Only- Locks and Alarms, or go to Educators-Locks and Alarms.

Where To Locate Locks and Alarms

- Local hardware stores.
- Radio Shack
- Stores that sell child safety products – Toys R Us, Babies R Us

Brands or Product Names

- First Alert
- Safety 1st
- Kidco

Web Sites

- www.radioshack.com
door alarms and chimes, portable motion detectors alarm/chime
- www.safetyandsecuritycenter.com
Door and window alarms, door knob alarms
- www.alzstore.com
(Alzheimer’s Online Store)
 - Invisible cabinet locks – magnetic locks (additional keys)
 - child-proof refrigerator latch (good for the less aggressive)
 - door and window alarm
 - seat belt alarm
- www.babyuniverse.com
Tot locks – magnetic locks (additional keys), door alarms

Other web sites may also offer these products. This is just a sample of sites that parents have shared.

Show & Tell

View From the Home Front

Kendra Goes Out Dancing

Here is a picture of my daughter, Kendra, age 17, taken on New Year's Eve at the gala she attends every year. She hands out roses at this event. And gets to dance after!



She does not live at home. She lives in a center for children. It is not PWS home only. I take what I learn and give back to the doctor, nurses, and all involved and we discuss and come up with her plan.

She has an excellent behavior management specialist there as well. Her plan is very, very specific.

I have seen major changes in Kendra this past year. Still bumps, but not as rough. She is very active. She has a buddy that

volunteered to take her to Curves 2x/ week. She is involved in Special Olympics, and ran this year for the first time. She is in scouts. Attends confirmation. She also has a job coach and works at the Humane Society and the nursing home. She loves her jobs, and the money she gets!

Peggy Sorge, Walcott, North Dakota

Love Is All You Need

This morning when she woke up, I took my 4-year old daughter Emily (PWS UPD) to the potty. This is the conversation that we had.



"You know what?" she asked.

"What?", I answered.

With a big smile, she said, "I love you!"

I answered "Thank you Emily, you know what?" "What?" she replied.

"I love you too!" I said.

Then with wisdom way beyond her years, she smiled as she said to me, "Then that's all we need to do."

I reached out and hugged my little girl to me, and said, "You're right, honey, that's all we need to do." I promise, Emily, I will never forget this moment and your very true words.

Beverly Folmer, Hockessin, Delaware

What I Learned at Conference

This was my first year attending the annual conference (2006). After this year, I hope to be going every year!

I think I learned more about PWS and the different effects it has in our kids in the two days I was in New York than the last two years my daughter has been alive.

The information that I learned I couldn't get anywhere else and I did learn a lot.

The other great thing was meeting different parents and kids and not having to have our conversations revolve solely around *explaining* PWS and how MacKenzie is doing. The people I met already knew that; therefore we could talk about other things and get to know each other, not having to get to know PWS again.... I felt I was with people that were like me, who love their children unconditionally and needed to know more about their abilities/disabilities but didn't want to have to sit there and explain everything they learned to someone who doesn't understand....

I felt so comfortable that I didn't want the conference to end. I would recommend anyone that is able to go to [2007] to go — you won't be disappointed.

*Cory Hacker, mom to MacKenzie, age 2 w/PWS
Neenah, Wisconsin*



A Caring Gift From a Special Young Man

Alec Jones, age 13 from Elyria, Ohio (shown at left), was diagnosed with PWS shortly after he was born. About a year ago he received for his birthday a beautiful bright red Kent X-Power bike.

He and his dad worked hard to get Alec up and riding on the bike. They tried training wheels, changed the seat, but it just didn't work. Recently, after still no success, he had become too big for it, with his knees almost hitting the handlebars. His dad realized Alec wasn't going to be able to use the bike and asked him what he wanted to do with it.

Alec knew exactly what he wanted to do. He wanted to donate it to their newspaper's toy collection for kids that don't have any. His dad had bought it for him, hoping he would be able to ride it, but in the end he was happy — and no doubt proud — with his son's decision.

Bracelets Benefit PWS

Nicole Burns, who has PWS, has a web site where she is selling bracelets www.jewelrybyNIKKI.com. She educates people about the syndrome on this site and will donate part of the proceeds to PWSA (USA).

Aloha from Corbin Soo

The results are in. In the 5K run, Daddy and I placed 60th out of 4,464 finishers and 6th out of 177 in Daddy's 40-44 old man division. The event raised over



the \$120,000 goal for Oahu schools' use in physical education. Daddy's and my contribution will be going to Queen Liliuokalani Elementary where I attend preschool. Overall, it was a fun morning in Waikiki, just slightly warm and humid for ideal race conditions, so I just napped in my cozy stroller through the race—no problem. Later, I enjoyed my water and

my favorite, bananas, for refreshments. Whew! What an exciting and fun event of physical activity.

Now I think it's time for me to take another nap. Corbin is 3½ and lives in Honolulu, Hawaii with mom and dad.

We Made Her Day

Shortly after a letter went out to all grandparents, a \$100 donation arrived at PWSA(USA) along with the following note from a grandmother: "Enclosed is a donation for PWSA. Also a big thank you for my grandparent's card; you made my day!"

Joshua Wants A Pen Pal

My son Joshua is 13 years old and was diagnosed with PWS at the age of 4. He had always gained weight and struggled to lose it.

This school year he got involved in athletics, assisting the coaches at the Junior High in Dumas, Texas. He is Football Manager and loves it! He also plays the bass clarinet in the marching band.

In the two months after school started, he has stayed busy and active — and lost 22 pounds!

We are so excited for him and so is his endocrinologist. I informed the teachers and school personnel of Joshua's GREAT job, and they, too, were very excited.

My Joshua would love to attend the conference in Dallas in 2007. He really wants to meet other kids who have the same syndrome as he. He would really like a Pen Pal, too. — Josephine Valdez, Cactus, Texas

Ed.Note: If you would like to correspond with Joshua, please contact the PWSA (USA) national office.





Make Your Way to the 29th Annual PWSA (USA) Conference This Summer

Our annual national PWSA (USA) conference is fast-approaching and we're expecting a great turnout! The conference is being held in **Dallas, Texas at The Hotel InterContinental Dallas.**

The Conference includes a **Scientific, Provider and Chapter President/Affiliate Day on August 1** followed by the **General Conference on August 2 and 3.** The annual Gala Banquet will be held on Thursday evening, August 2.

The two-day **General Conference** is a parent/caregiver-oriented program that brings together parents, caregivers, world-renowned scientists, clinicians and professionals in the field of PW. General Conference includes several sessions of interest to all attendees, as well as breakout sessions organized into topics specifically geared toward the issues and achievements of Adult, Youth (school age) and Children from age 0–5. Look to the next Gathered View for more details on the track topics.

The conference also includes a **structured care program for people with Prader-Willi syndrome.** We divide the programming into a **YIP** (Youth and Infant

Program) for ages 0–5 and a **YAP** (Youth and Adult Program) for ages 6 and up. All programming is age appropriate and directed and supervised by trained volunteers and staff. An exciting and self-esteem-enhancing program is being planned for YAP.

Conference registration will be available April 1 on the PWSA (USA) website. PWSA (USA) has secured a block of rooms at the Hotel InterContinental at the discounted rate of \$119 a night for up to four in a room. Hotel reservations can be made at any time through Globetrotter Travel by phone at 800-322-7032 (Ext. 2), e-mail pwsa-usa@globetrottermgmt.com, or online at www.globetrottermgmt.com/pwsa-usa.

Don't miss the opportunity to meet new friends, renew old friendships and learn the latest in nutrition, clinical care, research, and therapies. It's an event that the whole family will remember for a very long time.

To learn the latest about conference presenters and invited speakers, go to the conference website at www.pwsausa.org/conf

Beth - continued from page 1

Beth lives in a group home in Albemarle. Her mother Penny had spent seven years struggling with government agencies and Arc to get a designated Prader-Willi group home with the modifications needed. Since then, a second house has opened. The house plans now call for locks on pantries, kitchens and even trash cans, all necessary safety precautions for persons with PWS.

At one time Penny was a member of the Board of Directors of PWSA (USA) and president of the North Carolina chapter. Both of these positions she had to give up when she was diagnosed with fibromyalgia. She currently serves on the Board of Directors of The Arc of Stanly County. She notes with pleasure that she and Beth really enjoyed each other on the trip to San Diego and had a wonderful time. The past two or three years have brought a maturing to Beth that Penny sees and appreciates.

"Everyone should have as much independence as possible," says Beth. "I love being involved with the people in my hometown and have tons of friends. Most of all, I want to represent people with disabilities and show that we, too, have hopes, dreams and abilities."



Grandparent Book Now Available

The Grandparent Book, revised in 2007 by Barb McManus and Michelle Leightman, is a booklet by grandparents who've "been there" for grandparents who've learned that their beloved grandchild has PWS. Reading it will lead grandparents to better understand how to get help, offer help and be supportive.

Thanks to a grant from the Gerald J. & Dorothy R. Friedman New York Foundation, we are able to provide this booklet to grandparents free of charge. Please e-mail us at reception@pwsausa.org their direct mailing address and the child with PWS to whom they are related, or call us at 1-800-926-4797.

Raising Funds and Awareness for PWS

By Jodi O'Sullivan, Director of Community Development and Jane Phelan, Editor

Clunk, clunk, clunk, clunk, woooo! "That's how my son Shane described the sound of bunco," writes **Kate Loper**, grandparent to **Logan, 6½, who has PWS**. "The only sound in the room of 52 players is the roll of 39 dice until somebody gets a baby bunco (Wooo!). Then a genuine cow bell sounds when the head table gets a bunco." Do they know how to have fun in Washington or what?

The Bunco Tournament and Wine Tasting with Silent Auction, Raffles and Drawings netted \$5,072 for PWSA (USA) last October. Kate's son Shane dressed up in a tuxedo to MC and entertain guests at this event, which clearly had something for everyone to enjoy, while Logan "worked the crowd." Kate and crew will do a repeat this year. "I take credit for carefully selecting my team," Kate reported.

Keep on dancin'! The **3rd annual Jack Martin Bevacqua Dinner-Dance** netted more than \$20,400 to benefit research, PWSA (USA) and an educational seminar for the PWSA New Jersey chapter.

"Wow, this gets easier and better every year," writes **Chris Bevacqua**, aunt to Jack, 4, who has PWS. The event at the Port Monmouth, New Jersey VFW includes music, buffet and silent auction, and is run by family and friends.

"It was the biggest crowd and most successful silent auction yet. My sister-in-law **Christie** (Jack's mom) spoke about PWS and Jack's progress over the year as she usually does. She got very emotional... because last year Jack wasn't walking at this event and this year he was dancing. Everyone noticed and was so happy!" Chris reports.

"We began the first year raising \$12,000 and the second \$15,000 and now \$20,000. It is some work but worth it in the end. Not just for the money we raise but for the fun everyone has. Every time a merchant whom I solicit to look at me crazy when I say it is for Prader-Willi syndrome I know I am able to educate one more person."

Sybil Cohen, president of the PWSA New Jersey Chapter, created an appeal letter called **Rose's Garden**. Named for her daughter **Rose, 12**, with PWS, the letter to family, friends and co-workers netted more than \$2,000 for research and awareness. "PWSA has been a life line for so many families... This support is vital for so many families and I wanted to be able to help support these programs," Sybil reports.

Hers was a very easy and inexpensive undertaking that took a few hours to write the letter, make photocopies, address and stuff the envelopes and add postage, says Sybil. "The outcome was well worth the effort! I encourage anyone who has thought about doing a fundraiser for PWSA to consider doing a simple mailing of their own.

Ryan O'Sullivan of Ohio [husband of Jodi] ran his **fourth annual marathon** in honor of his niece **Josilyn Levine, 4**, of Florida, who has PWS. This time he netted \$7,268 for PWSA (USA) at the New York City Marathon. Ryan says he's touched by the encouragement and support received from friends and family, plus "a woman associated

with PWS that I do not even know made a very generous donation just because she thought it was a great cause." Ryan also received a generous donation from his company. "You never know who is going to give so it never hurts to try."

Kelly Devlin and her fiancé ran the Philadelphia Half Marathon in honor of Kelly's niece **Avery Waldrop, 1, of Virginia**, who has PWS, and netted \$5,986 for PWSA (USA). They more than met their goal to increase PWS awareness and raise funds to develop effective treatments for those impacted by PWS!

**I am one, but still I am one.
I cannot do everything,
but still I can do something.
And because I cannot do everything,
I will not refuse to do that something I can.
~Edward Everett Hale**

Bobbi Martello of Cocoa Beach, Florida, aunt of **Madison Hurdle, 4**, of Colorado, with PWS, netted \$4,704 for PWSA (USA) from her **2nd Annual Madison Hurdle Softball Tournament** held in December 2006. Baseball runs in the family: Madison's dad **Clint Hurdle, PWSA (USA)'s PWS Awareness Month spokesman for 2006 and 2007**, manages the Colorado Rockies baseball team.

"When Madison was born and diagnosed with PWS, I had no idea what that was and felt helpless. I think my inspiration comes from not wanting other people to feel the way I did, so raising money for education can help in that fight," Bobbi writes. "Can't wait till next year!" Doesn't she sound like a ball player?

Can't run? Walking is good, too. With **PWSA of Ohio, Jennifer and Brad Bolander** organized **Sophie's Walk** in honor of their daughter, age 3, who has PWS. Also planning the event were **Steve Fetsko**, president, PWSA of Ohio and **Jack Shiley**, treasurer, and **Jim Bolander**, grandpa to Sophie and member of the Olmsted Falls Kiwanis which provided event assistance. Altogether the event netted \$4,500 to benefit both the Ohio chapter and PWSA (USA). Included were clowns, music, crafts, games, door prize drawings and special T-shirts to order. "I am really glad I did this," writes Jennifer. "Both the funds raised and the amount of awareness built up are very exciting, and boost my belief that fundraising is important, it definitely makes a difference, it is building a positive future for Sophie and for all the children and adults out there who live with PWS every day."

If you'd like to join the fun in 2007, contact the chapter at www.pwsaohio.org.

**Does your employer support your
donations with a matching funds program?
If so, please call us at
1-800-926-4797**

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.

Joseph Allan Polege



Joseph (Joey) Allan Polege passed away on December 31, 2006 with the RSV virus at age 3½ at Children's Hospital in Dallas, Texas.

Born July 7, 2003, Joey was always a cheerful young boy with lots of smiles all the time.

He had just started to learn to say a few words, including Mom, Grandma, Grandpa, Auntie and a few more, wrote his mother, Catina Polege.

"Joseph is in the arms of his Great Grandma now. He will be missed by all who knew him. Every day is a lonely day without him here on Earth with us. But we know that one day we will be there with him," she stated.

Our PWSA (USA) Bereavement Program is coordinated by volunteer Norma Rupe. We offer free bereavement materials for our members, along with envelopes for memorial donations. For more information please contact PWSA (USA).

Cindy Elloise Fankhauser

Cindy passed away peacefully in her sleep on December 7, 2006 in Grandview, Washington. Born in Salem, Oregon, Cindy spent her first 35 years in Richland, where she graduated from Richland High School in 1979.

Cindy loved everyone; especially the children she worked with and her nieces and nephews who adored her.

Cindy loved spending time doing jigsaw puzzles and was proud of the many medals she won bowling in the Special Olympics. Cindy was loved and will be missed by many friends and family members whose lives were blessed by her servant heart, big smile, and infectious laughter.

Cindy was preceded in death by her father Ed and is survived by her mother Joanne; sister Carole Cox and brothers John Fankhauser and Don Fankhauser.

The family suggests memorial contributions be made to PWSA (USA) or the Bethany Presbyterian Church (201 Birch, Grandview, WA).



In Honor Of (continued from page 16)

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Thank you for Contributions through January 2007

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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National Organization for Rare Disorders
2006 NATIONAL ORGANIZATION MEMBER

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. PSWA (USA) is supported solely by memberships and tax-deductible contributions.

