

IUSCC PINK

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Dear Friends,

Hot flashes can be annoying for many women. Your hot flashes might start as part of the natural aging process. Or you might start having hot flashes when you stop hormone therapy or start taking medications like chemotherapy, tamoxifen, exemestane or letrozole. Research shows that hot flashes occur many times during the day and night and are often very severe and bothersome. They can disrupt your mood, sleep and daily life. Unfortunately, health care professionals do not know the exact cause of hot flashes. This makes hot flashes difficult to treat.

As a nurse scientist at the Indiana University School of Nursing and member of the IU Simon Cancer Center, for the past 12 years, I have studied hot flashes in women with breast cancer. Some of the important findings from my research are:

- Nighttime hot flashes and poor sleep are common in breast cancer survivors.
- Breast cancer survivors might sleep through some nighttime hot flashes - but these hot flashes might still disrupt sleep.
- Hot flashes in breast cancer survivors have some differences from hot flashes experienced by menopausal women without cancer.
- A medication called venlafaxine (Effexor) reduced hot flashes in breast cancer survivors but most women chose not to stay on this medication for longer than a few months.
- If a treatment decreases your hot flashes by 50%, it might also help improve your mood and sleep

I am leading Indiana University's involvement in a new initiative to find safe and effective treatments for hot flashes. The initiative establishes a multi-site research network to conduct clinical trials of promising treatments for the most common symptoms of menopause. The initiative—Menopause Strategies: Finding Lasting Answers for Symptoms and Health (MsFLASH)—is led by the National Institute on Aging in collaboration with the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Center for Complementary and Alternative Medicine and the Office of Research on Women's Health. The MsFLASH network will be coordinated by principal investigators Andrea Z. LaCroix, PhD and Garnet Anderson, PhD, both from the Fred Hutchinson Cancer Research Center in Seattle. The network centers are funded for five years. Other clinical sites are: Harvard Medical School, Boston; Kaiser Permanente, Northern California; University of Pennsylvania School of Medicine, Philadelphia; Group Health Center for Health Studies, Seattle; and University of Washington School of Medicine, Seattle.

My teams at Indiana University and the IU Simon Cancer Center have a long-standing commitment to improving the health and well-being of breast cancer survivors and all women. See page 5 for more information on our current hot flash management trial.

-Janet Carpenter, PhD, RN

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Many Stages of Cancer

What do you do when someone you love tells you they have cancer? You listen! There are so many stages your loved one will go through and many times they just need someone there to listen. When my sister, Judy Enis, told me she had breast cancer, I listened. When she was questioning “why me”, I listened. She had been diagnosed with cancer for the second time. Judy had survived cancer of the uterus and cervix. She had a hysterectomy and underwent radiation treatments. Judy had been cancer free just one month short of 11 years when she found the lump in her breast. No, for various excuses, she had not had a mammogram for three years. She did self-exams. However, by the time she found the lump, in July, 2007, Judy was already in Stage 3 of breast cancer. (Ladies Please Schedule Those Mammograms)

Judy lives in a small rural community

with a very small community hospital nearby. Her doctor told Judy if she wanted the best care, she should go to Indiana University Melvin and Bren Simon Cancer Center. She questioned what she should do. I listened. It would be about a two hour drive each way to come to Indianapolis for treatments. It would be a burden on her extended family to drive her to and from the treatments when she was so sick she couldn't make the trips by herself. Should she have a lumpectomy or a mastectomy? She asked what she should do. I listened. I gave Judy my opinions, but told her the ultimate decisions were hers. Between driving to and from Indianapolis, seeing doctors, and infusions; sometimes Judy would be gone from home 12 to 14 hours a day. Since I live in Indianapolis, I told Judy I would attend every appointment I could to support her. During the two year period I only missed 2 appointments.

There was a time when Judy forgot to buy new batteries for her hearing aids and I listened to be sure she heard and understood what the doctors and/or nurses were telling her. After the visits, I would go home and call, text, or e-mail friends and family to give them an update. In e-mails I asked friends and family to pray for

her. We showered her with Get Well / Thinking of You cards. This gave her something to look forward to instead of thinking about how sick she was. Getting mail was the highlight of many of her days.

During her infusion visits, we would talk and laugh so much the nurses said they wanted to bottle the endorphins we were spreading and share them with the other patients. This was such an important stage for trying to keep everything positive. If Judy's feet were hurting or tingling because of the meds, I would bring some body lotion and give her a foot rub while she had her infusion treatment. One time I gave her a foot rub because her blood pressure was too high. They said it wasn't safe to give her the infusion unless her blood pressure came down. It worked!

At one point, Judy was so sick she had to go into the local hospital. In addition to complications from chemo,

she had pneumonia. This was the stage where Judy was praying to God to just let her die and go home with Him. We are thankful He had a plan and these were some prayers He did not answer. At the same time Judy was in the hospital, her husband had to be airlifted to a hospital in a neighboring state after a bad motorcycle accident. Believe it or not, we feel this turned out to be a blessing in disguise. Her husband was off work for 6 months. This was Judy's sickest stage and he was able to be at home to help take care of her. At first, his injuries limited what he could do to help her. Sometimes it was things as simple as to keep the two grandsons and a foster son they are raising quiet. No matter how small, we take our blessings where we find them.

While Judy was in the hospital, she started losing her hair. I made a hat out of newspapers for her. I tied a pink ribbon around it and stapled long pink curls on each side. It was just a little something silly, but it lifted her spirits! After Judy was home from the hospital, she decided it was time to shave her head. Her beautician was so kind. She asked Judy to come in during her lunch hour. She locked the door so Judy would have her privacy during this very traumatic stage of having

There are so many stages your loved one will go through and many times they just need someone there to listen.

By Karen Delight Hahn

cancer. The family told Judy she was bald and beautiful! Judy was thankful to the volunteers who made hats and left them at IUSCC for the cancer patients. We hope they realize just how much the hats mean to the ladies who had lost their hair.

One of the next stages was to buy a wig. But because her husband had been off work for several months and of all the expenses they both incurred, money was tight. Then out of the blue, a man stopped at my parent's house and gave my father \$100 to give to my sister to buy a wig. He said his wife came to him and told him to give the money to Judy to buy a wig. Well! The wig did so much to raise Judy's spirits. The wig was styled similar to the way Judy wore her hair in high school. It made her look so much younger and she was so much happier. Of course, all of us (even our 3 brothers) tried on the wig. But none of us looked as good in it as Judy did. Every time she walked by a mirror, she would look at herself and thank her benefactor. When Judy called to thank him, they talked for 45 minutes. He had listened to a force guiding him to reach out and help someone he knew, even though not well. He listened and it was a good thing ... for both of them.

At our family reunion, Judy got up and said how happy she was to be able to attend another reunion. Everyone listened. With help from family and friends, Judy was able to stay positive at almost every stage she faced. I realize these are not the stages the professionals mention when discussing

cancer. You know: denial, anger, acceptance, etc. Over the two year period of her ordeal, of course, there were many stages I have not mentioned. But the ones listed here are some of the stages in Judy's life with cancer which stand out in my mind. Each cancer patient will have their own stories. I know there are those who will be sicker; those who will live farther away from treatment centers; or those who have more financial problems. However, I doubt there is anyone who has more positive support from their family and friends than Judy has had. A great support group can help you through any catastrophe.

Once again, Judy Enis is a survivor!!

Laugh, love, remember, and look forward... LISTEN to what your loved one needs at whatever stage they may be in at that time.



Editor's Note

As we all know October is breast cancer awareness month and we see pink everywhere we look. The other day I had an article from the Boston Globe titled "Sick of Pink" forwarded to me. The article speaks about how women with breast cancer feel like companies are profiting off of their pain. One woman states, "October is just a reminder of my cancer."

I do have to preface this article by saying that I am not a breast cancer survivor. As the editor of this newsletter I am a breast cancer educator, but at heart I am a breast cancer researcher. I know many of you who have and are fighting this disease. I also see friend's from college who have lost their mom's to breast cancer. And I know the children and grandchildren who will not grow up with their moms or grandmother's hugs and kisses. Honestly the article in the Globe makes me sick!

Ok, yes I am sure there is a profit made on many of the breast cancer products that are being sold this month. Companies wouldn't stop their manufacturing processes to make a line of pink items if they weren't going to benefit. But I like to look at the positive side of these products:

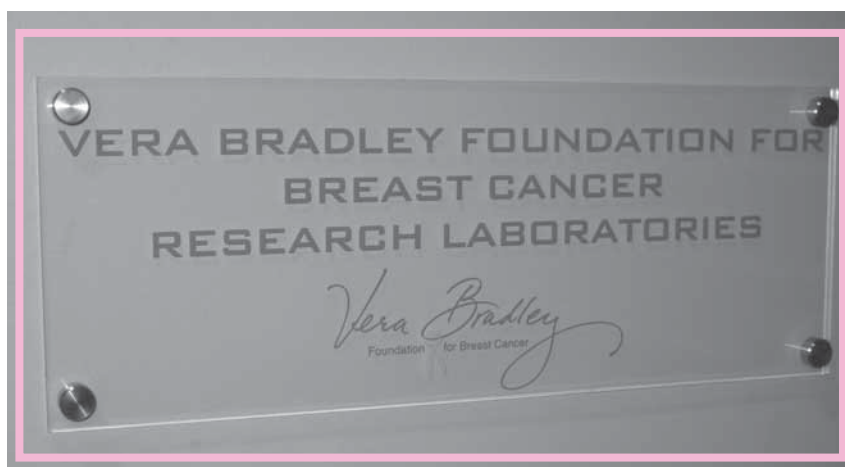
- They produce millions if not billions of dollars in research funding. A lot of the money funds research right here at IUSCC. Last year alone Susan G Komen for the Cure (national) funded more than \$7 million worth of research here. And these are projects that will make a difference in cancer research such as the Susan G Komen for the Cure Tissue Bank. If you want to see pink product funds at work walk over to Walther Hall at IUPUI. The second floor of the building is the Vera Bradley Foundation for Breast Cancer Research Laboratories. These labs and many of the researchers are paid for with profits from the sale of purses in colors such as Hope Garden and Pink Elephants.

The money produced by all the pink products doesn't disappear into oblivion. It funds expensive research and without it finding a cure will be more difficult.

- My second response to those sick of pink, is that the pink products allow everyone to support a cure. Whether it's the fashionista who likes the pink shirt at the mall or the mom buying pink cans of tomato soup at the grocery store, most people don't have thousands of dollars to give to the cause. They can buy products that contribute to breast cancer organizations and make a difference.

- Lastly, pink products are a reminder that breast cancer exists and hopefully a reminder for women to be proactive about their health. If that pink can of tomato soup encourages one woman to get a mammogram, then it is not only funding research, but saving a life.

For those of you that love seeing all the pink products and even football players in pink shoes, I do warn you to read the labels on pink products. Make sure the proceeds are going to a nonprofit organization such as the Breast Cancer Research Foundation or Susan G. Komen for the Cure and not to a company that just slapped a pink ribbon



on their product to increase sales.

I say bring on the pink toothpaste, football uniforms,

and anything else you can turn pink. Think of pink as a symbol of how far we have come. Think of it as the color of a cure.

-Casey Allen, CCRP-Editor IUSCC Pink



Our featured web site for this edition of IUSCC Pink is the Breast Cancer Research Foundation. "The mission of The Breast Cancer Research Foundation® is to achieve prevention and a cure for breast cancer in our lifetime by providing critical funding for innovative clinical and

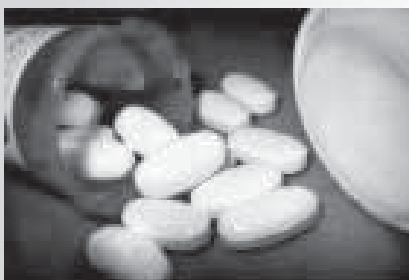
translational research at leading medical centers worldwide, and increasing public awareness about good breast health. A minimum of 85 cents of every dollar goes to research and awareness programs."

The web site www.bcrfcure.org has sections on the research projects that they fund and an awesome section for shopping pink. The get involved section has information on community programs, ways to donate, and the Survivors' Circle Partners. "The BCRF Survivors' Circle Partner Program is for survivors involved in small businesses who want to donate to BCRF to help fund the work of the best researchers in the world to end this disease." This program offers many unique products that benefit breast cancer research.

The site also provides an extensive "Research in Action," section where you can learn about each grantee, including IUSCC award recipients Dr. Sledge, Dr. Miller, Dr. Stornolo and Dr. Clare. There is a meet the researcher Q & A segment where you can read more about specific research projects. The section is rounded out by scientific news and videos that feature award recipients. The news section has lots of articles about research published on breast cancer along with archived, older research findings.

The Breast Cancer Research Foundation's site is very informative and gives a clear picture of how funds raised through the foundation are used. It also has an enormous amount of information on current breast research projects. Visit the site to see where your pink product money is going or to learn more about items that support breast cancer research.

Our next issue of IUSCC Pink will focus on Clinical Trials. If you have questions about clinical trials or would like



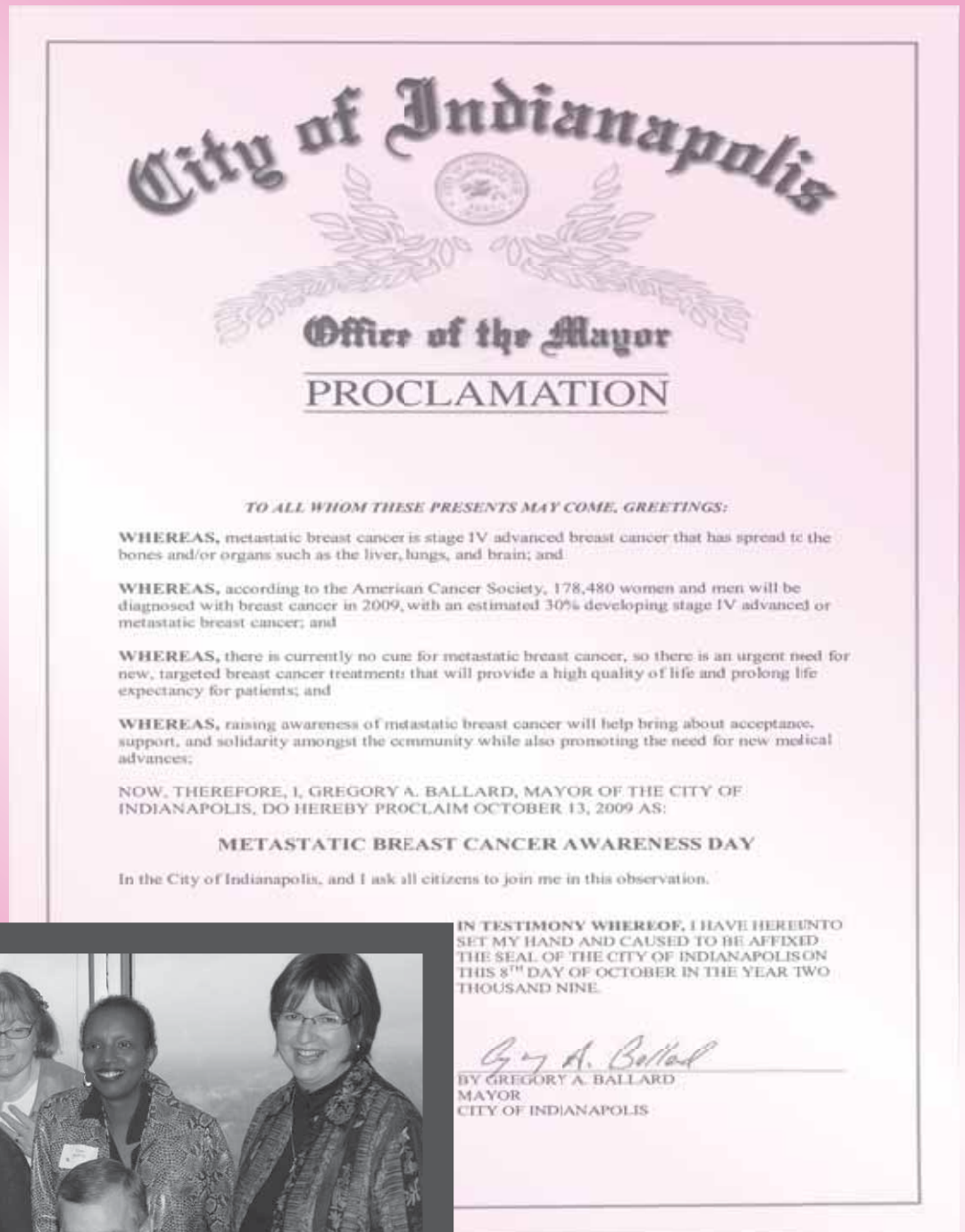
to share your story about participating in a clinical trial please email Casey Allen at calallen@iupui.edu. We would love to answer your questions and share your stories.

Breathe for Hot Flashes

With funding from the National Cancer Institute, Dr. Carpenter is leading a team to study a unique way to manage hot flashes without medications. This treatment is not available anywhere else at this time. The study is including breast cancer survivors and women without cancer. Women who qualify take part in 3 to 4 study visits during a 4 month period. Women are placed into 1 of 3 groups to learn ways to breathe for hot flashes. One group receives a CD with instructions in the mail. A second group receives a DVD in the mail. The third group does not get materials until the end of the study. Women who take part fill out some paperwork, have their height and weight measured, and press buttons on a monitor to tell the researchers about their hot flashes. Parking on campus is paid and participants receive a \$25 giftcard after each visit for their time and effort. Carpenter hopes that this uniquely designed treatment will help women with their hot flashes now and in the future. If you are interested in participating in Breathe for Hot Flashes contact the study team at 317-278-6094.

Indianapolis declares Metastatic Breast Cancer Day

Indianapolis, Indiana joins the list of cities and states to declare October 13th Metastatic Breast Cancer Day! Metastatic (stage IV) breast cancer is defined by the spread of breast cancer to other parts of the body -- most commonly the lungs, liver, bones and brain. Six stage IV breast cancer survivors from Young Survival Coalition & Breast Friends Indy met with Mayor Ballard and he signed the Metastatic Awareness Day Proclamation.



Pictured from left to right: Krysti Hughett, Vanessa Santos, Cindy Day, Linda Batchelor-Ballew, Toni Burts and Debra Porento (a combined total of 18 years of living with metastatic breast cancer)

Is there an increase in osteoporosis after BC treatment with surgery, radiation, and chemo?

Osteoporosis is linked to menopause and estrogen deprivation. Therefore, there is a risk of osteoporosis during breast cancer treatment. For instance, chemotherapy can induce premature menopause, which is linked to bone loss. In addition, the use of the newer generation of hormonal blocking agents, the aromatase inhibitors, has been associated with bone loss. Measurement of bone density during treatment with these agents is generally recommended.

How do you decide when to schedule reconstruction at the same time as the lumpectomy/mastectomy vs reconstruction at a later date?

Reconstruction should be considered for any woman who is undergoing a mastectomy. The first consideration is the patient's general state of health. TO MINIMIZE YOUR RISK OF COMPLICATIONS AFTER RECONSTRUCTION YOU MUST STOP SMOKING. Most reconstructions can be at the time of the mastectomy. Exceptions include patients who will require post-operative radiation therapy. This is necessary in patients with multiple positive lymph nodes, chest wall involvement, skin involvement, and after surgery for inflammatory cancer. Partial breast reconstruction is an option to augment a breast after lumpectomy. We do not do this as an immediate procedure because there are no reliable ways to assess the lumpectomy surgical margins intraoperatively. Once the margins are confirmed negative by the pathologist then partial reconstruction is an excellent means of achieving symmetry.

What percent of women who have had breast cancer get endometrial cancer?

Generally, this is a rare occurrence. Approximately 1% of postmenopausal women taking tamoxifen may develop endometrial cancer. Endometrial cancer is usually diagnosed in early stage; as such women would experience vaginal spotting or bleeding that leads to early evaluation. Endometrial cancer is curable with surgery alone or surgery and radiation. Extremely rarely (1 in thousands), women taking tamoxifen may

What is DCIS and what is the chance of recurrence?

Ductal Carcinoma In Situ is a type of breast cancer that's confined within the breast duct that does not invade the wall of the breast duct. This distinguishes it from invasive ductal carcinoma. Because DCIS does not have access to the blood stream, so it's potential to spread to other areas of the body is extremely low and the prognosis is generally very good.

Cancer Prevention Study-3 (CPS-3)

To better understand ways to prevent cancer, the American Cancer Society's Department of Research is recruiting 500,000 adults across the US and Puerto Rico for a new research study, the Cancer Prevention Study-3 (CPS-3). Enrollment will take place at select American Cancer Society offices.

Who is eligible to participate?

Anyone who:

- Is willing to make a long-term commitment to the study, which involves completing periodic follow-up questionnaires;
- Is between the ages of 30 and 65 years of age; and
- Has never been diagnosed with cancer (this does not include basal or squamous cell skin cancer).

For more information and to schedule your appointment, visit www.cancer.org/cps3 or call toll-free 1-877-217-4138

American Cancer Society
Central Indiana Area Service Center
5635 W. 96th Street, Suite 100
Indianapolis, IN 46278 317-344-7800

Collection Dates and times are:

- Tuesday, Nov. 10, 2009 from 10 a.m. to 2 p.m.
- Thursday, Nov. 12, 2009 from 4 p.m. to 8 p.m.
- Saturday, Nov. 14, 2009 from 9 a.m. to 1 p.m.
- Tuesday, Nov. 17, 2009 from 4 p.m. to 8 p.m.
- Thursday, Nov. 19, 2009 from 10 a.m. to 2 p.m.
- Saturday, Nov. 21, 2009 from 9 a.m. to 1 p.m.

ARE YOU INTERESTED IN LEARNING MORE ABOUT BREAST CANCER?

Sign up to receive the *IUSCC Pink* Newsletter

Name: _____ *E-mail: _____

Street: _____ City/Zip: _____

*Newsletters will be sent by e-mail when applicable.

Return to Casey Allen at:

Walther Hall (Building R3) - Room C246
980 W. Walnut St.
Indianapolis, IN 46202-5126



INDIANA UNIVERSITY

MELVIN AND BREN SIMON
CANCER CENTER

Or send an e-mail to calallen@iupui.edu with the above information.

Do you have a story idea or just something to say about a story you've read in *IUSCC Pink*? Tell us about it! Would you like to share a personal experience? Contact us via e-mail calallen@iupui.edu, call 317-274-0594 or send mail to the address above.

Past editions of *IUSCC Pink* can be viewed at the IU Simon Cancer Center Web site, cancer.iu.edu, by selecting breast cancer in the cancer type section (<http://cancer.iu.edu/programs/breast/iuccpink/>).