IUCC PINK

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On November 4, 2006, 32 women took time out of their day to be a "Friend for Life." They agreed to have breast tissue and blood collected to bank in Mary Ellen's Tissue Bank for scientists trying to learn what makes a normal cell turn malignant and causes breast cancer. To reward the ladies for their courage and time, Ology Spa and Clarian North Hospital donated half-hour spa treatments. Dr. Anna Maria Storniolo, director of Mary Ellen's Tissue Bank, constantly hears remarks about the value of donating tissue. "Women really want to do what they can to help solve this problem," says Storniolo. One volunteer remarked, "I couldn't write a check big enough to equal the value of giving my own DNA."

Dear Friends,

It is hard to believe that when I began my training in surgery (which doesn't seem so long ago) the standard breast cancer surgery was still the **radical mastectomy**; an operation that removed the breast, the muscles of the chest wall, and all the lymph nodes from the armpit. I witnessed the shift to the **modified radical mastectomy** (removal of the breast and lymph nodes with preservation of the chest muscles) and finally the adoption of breast preservation by **lumpectomy** (removal of the tumor with a rim of normal tissue). We have come a long way in what seems to be a blink of an eye. None of this would be possible without our courageous patients' participation in clinical trials and the support of thousands dedicated to the cause.



For women who must have or elect to pursue mastectomy, a variety of options are now available for **breast reconstruction or preservation**. The latest reconstructive option offered at Indiana University is the **DIEP Flap**, which harvests skin and fat from the abdomen without disrupting the abdominal muscles. For women who do not qualify for lumpectomy because of tumor size or location, we offer **neoadjuvant chemotherapy** (pre-operative chemotherapy). In the majority of cases this will result in reduction or elimination of the tumor, making breast preservation an option.

As the magnitude of breast surgery has decreased, so has the extent of the lymph node dissection in the armpit. **Sentinel lymph node biopsy** limits node sampling to one to three nodes in most cases. This significantly reduces the risk of post-operative complications like lymphedema (arm swelling) and nerve injury. Even the extent of radiation therapy is shrinking! Techniques are currently under investigation whereby only the tumor bearing portion of the breast will be treated with **accelerated partial breast irradiation** (APBI). We are currently offering women APBI as part of a prospective, multicenter clinical trial comparing these techniques to standard whole breast irradiation.

Appropriate local therapy significantly improves long-term survival, and we are committed to clinical and basic science research that advances local therapies. We are currently involved in the development of techniques that identify changes in the cells lining the milk ducts that predict a developing cancer. Our center was the first to demonstrate the feasibility of administering chemotherapy directly to the cancerous milk ducts using nanoparticle technology (extremely small particles). We are evaluating new technology to improve the diagnostic accuracy of sentinel lymph node biopsy. Members of our team are also interested in pursuing ways of destroying breast tumors without surgery called **tumor ablation**.

The future looks bright! Therapy keeps getting less disruptive, and we remain committed to the elimination of this disease. We look forward to a time when these procedures will be historical curiosities.

Robert Goulet, M.D.

The Five-Year Mark by Kelly Douglas



The five-year mark is a highly prized goal of cancer survivors. When fellow survivors reach this mark it is a cause for celebration and usually warrants at least going out for dessert or a cup of coffee. Those that have not yet reached their five-year mark look forward to it with wishful enthusiasm. Well, this fall was a monumental one for me. I finally reached that long anticipated goal.

Rolling back to the start of this five-year clock takes us back to September 2001. I was 24 years old, starting my career in industrial design and trying to start a family with my husband. We had just celebrated our second anniversary, and life was wonderful- except for this annoying lump in my breast.

Looking back my husband and I are amazed and very thankful that the cancer was caught. Women have to be their own advocates – you know your body best. At 24 years old, a few doctors didn't take my lump as seriously as I did. I was told to take some vitamin E and not to worry about it. Well, of course I did worry; otherwise I wouldn't be sharing my story today. Eventually, a fabulous nurse practioner sent me for an ultrasound and mammogram. At the end of the ultrasound I mentioned that I really, really wanted a mammogram as well. The doctor looked down at me and shrugged. He went ahead and sent me for the mammogram in the next room. I didn't realize it, but at the time, the ultrasound didn't show any cancer. You know it's bad when the nurse comes back in, apologizes and asks you to disrobe to do more views – THREE TIMES! After the third time, I didn't bother getting changed again but just sat in the hospital robe and waited. When she came back, I was given information about a breast surgeon with whom they already made an appointment for me. The one thing that I remember was that the nurses had such a soft look in her eyes. I think that this scared me even more.

My husband and I had a long two-year journey of surgeries and treatments. We were both quite involved in my treatment. It helped that my husband is a family nurse practioner and a bit of a Type A personality. We had thoroughly researched every step of my treatment. We didn't have to, as I feel we had the best doctors, nurses and staff possible! But it was helpful to know about each step and what it entailed.

I think that the worst part was the biopsy. As much as I had read about what it was going to be like, I was not prepared for the 3 long wires inserted into my breast and tagged with little balls to help indicate what needed to be cut out. This was a lot more than I had thought was going to be cut out. The biopsy showed that I had lymph node positive breast cancer.

There wasn't a choice between a lumpectomy and a mastectomy. I had to go with the mastectomy. There was a bit of a choice on the reconstruction, when to do it, how to do it and silicone or saline for my implants? Way too many choices to deal with in the midst of coming to terms with the fact that I had cancer. I was resentful that I even had to have a breast implant. I had always been quite happy with my body, and I had sort of looked down on plastic surgery. Now I was looking at headless photos of breasts, much older breasts. No offense to any of the women who may have been in the photos, but it seemed that everyone looked better with their reconstructed breasts. I was quite certain that would not be the case for me. I was rather skinny, so I couldn't have flap reconstruction, which would have used my own tissue and generally looks more natural. This just left the

The Five Year Mark, contiued from page 2

tissue expander which meant the implant would be placed under my pectoral muscle after the muscle had been stretched out over about six months to accommodate the implant. This also meant that I would be able to move my right breast like a muscle man. It's kind of goofy – but when I'm eighty, I'm sure that it will impress the grandkids.

I credit my survival with participating in a clinical trial. It was determined that the cancer tested positive for HER2. There was a clinical trial for trastuzumab (Herceptin) going on and I could participate if I wanted to. I understood the benefits of trastuzumab from the research that my husband and I had done. I also felt that I needed to participate in the clinical trial. There were so many women that went before me and participated in clinical trials for the chemotherapy that I had already received. I feel such an incredible amount of gratitude to all of them. The best way that I can thank all of them is to participate in as many studies as I can to help those diagnosed after me.

A lot happens in five years, especially when it involves breast cancer. I have made a lot of new friends sharing the breast cancer journey. I have switched jobs a few times and even started my own company. My mother was diagnosed with breast cancer. And, unfortunately, I have lost some dear friends in their battle against the disease.

I had been looking forward to the five-year mark for such a long time. I had grand plans for a party or maybe just going out with some friends to celebrate. However, the day came and went, and I didn't remember until a week later.



Instead something even more important happened when my five-year mark hit – life. I was celebrating the life of our son who we adopted in early September, my life as a wife and mother, my husband's life and his achievements. Wyatt Edward Emanuel Douglas was born September 8, 2006 – almost exactly five years to the day that I found out that I had

cancer. I'm glad that he was the only thing on my mind as my five-year mark came and went.

For information about Young Survival Coalition visit www.youngsurvival.org

Who's That Behind Those Shades?



Dr. George Sledge "strutted his stuff" at the annual Y-ME fashion show luncheon celebrating breast cancer survivors. On October 14th, survivors and health care providers modeled for over 1,100 participants in a fashion show presented by Nordstrom.

Tuff Enough to Wear Pink



The Ohio Cowboy Mounted Shooting Association had their first "Tuff Enough to Wear Pink" Day at Miamitown, OH, on Saturday, October 7th. Cowboys and cowgirls participating in the mounted shooting event were asked to wear as much pink as possible to support Breast Cancer Awareness Month. Prizes were awarded for the pinkest cowboy, pinkest cowgirl and pinkest pony. Six hundred dollars was raised for the Catherine Peachey Breast Cancer Prevention Program at the Indiana University Cancer Center.

HER2 Status

What Does it Mean for the Treatment of Breast Cancer?

One of the most important things women and men can do after a diagnosis of breast cancer is to begin to learn about the disease. When you understand the characteristics of your breast cancer you and your doctor can make better decisions about your treatment. One of the important characteristics to learn about is HER2 status.

Breast cancers can be categorized as being HER2positive or HER2-negative. About 15 to 20% of women with breast cancer have HER2-positive tumors. HER2-positive breast cancer has more than the normal number of HER2 genes in the cells of the tumor. This means that there are more HER2 receptors on the surface of the cells. The receptors are activated and once activated the receptors send signals to the cells to grow and divide.

Studies^{1 2} indicate that the drug trastuzumab (Herceptin) is effective in the treatment of HER2-positive early stage breast cancer and HER2-positive metastatic breast cancer (cancer that has spread to other parts of the body). Trastuzumab specifically targets and binds to the HER2 receptors on the tumor cell surface and may decrease the number of messages sent to the cell that tell it to grow and divide. Trastuzumab may also signal the body's immune system to destroy cancer cells and may work with chemotherapy (e.g., paclitaxel/Taxol) to destroy HER2positive cancer cells. Trastuzumab does not treat HER2negative breast cancers.

There are two methods of testing for HER2 status in women with breast cancer: immunohistochemistry (IHC) and fluorescence in situ hybridization (FISH). The tests are done on breast cancer tissue taken during surgery or a biopsy. Results from both tests are used in the clinical setting and the results of the tests influence treatment choices.

IHC is a protein-based test that is used to provide an assessment of the amount of HER2 protein receptors on the surface of the cancer cells. In HER2- positive tumors there are more HER2 protein receptors than in HER2-negative tumors. The scoring for an IHC test is from 0 to 3+.

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- o Zero is HER2-negative
- o 1+ is considered HER2-negative
- o 2+ is considered a borderline or equivocal result
- o 3+ is HER2-positive

If an IHC test is reported as 2+, a FISH test is performed.FISH is a gene-based test used to determine the number of HER2 genes in the cells of the tumor. In HER2positive breast cancer there are too many copies of the HER2 gene. The results of a FISH test are given as has been HER2positive or HER2-negative.

How the HER2 Gene Works in Breast Cancer



HER2-positive cancer cell with extra receptors on the surface of the cell.



Herceptin attaches to the HER2positive cancer cells.



Herceptin may signal the body's immune system to destroy the cell.

HER2 Status, Continued from page 4

HER2 status of a breast cancer tumor can be found on the pathology report. Every patient needs a copy of this report. For help understanding the pathology report you can read the booklet *Your Guide to the Breast Cancer Pathology Report* at breastcancer.org http://www.breastcancer.org/ pathology intro.html or order the brochure *Understanding* Your Pathology Report: A Guide for Breast Cancer Patients (2004) from Y- ME National Breast Cancer Organization at http://race.y-me.org/site/ PageServer?pagename=OrderYMEPublications.

Source: Research Advocacy Network, Judy Perotti author

¹<u>Romond EH, Perez EA, Bryant J, Suman VJ</u>, et al *Trastuzumab plus* adjuvant chemotherapy for operable HER2-positive breast cancer. N Engl J Med. 2005 Oct 20;353(16):1673-84.

² Slamon DJ, Leyland-Jones B, Shak S, et al. Use of chemotherapy plus a monoclonal antibody against HER2 for metastatic breast cancer that overexpresses HER2. <u>N Engl J Med.</u> 2001 Mar 15;344(11):783-92.

Breast Cancer Quiz

1. One in nine women will develop breast cancer in their lifetime.

> o true o false

2. Women over the age of 50 have an increased risk for developing breast cancer.

> o true o false

3. Men do not get breast cancer.

o true o false

4. Breast cancer is the most common cancer diagnosed in women.

> o false o true

- 5. Breast cancer kills more women than lung cancer. o true o false
- 6. Most women who develop breast cancer have a family history of breast cancer.

o true o false

7. Infiltrating (or invasive) ductal carcinoma (IDC) is the most common type of breast cancer. o true

o false

8. A lump in the breast, discharge from the nipple, changes in how the breast of nipple looks, such as dimpling or redness are common signs of breast cancer.

o true

o false

True 1, 2, 4, 7, 8 False 3, 5, 6,

A Precious Gift

To live each day in fear trying hard to hold back tears. Not knowing, what to say I don't think God meant for it to be this way. Will He take her or let her stay? Will He decide that it's her day? As much as we trust in the ever after, none of us wish for life to go faster. Each person's soul is a precious gift we never know when life will shift. One day you're up, the next you're down. One moment you smile, the next you frown. As I look back over the years, the memories I hold are very dear. Though I don't know what's to come, I know I've been more blessed then some. I find myself holding tight to my faith, and pray everyday God will keep us safe. Dear Lord remind us each day that you are here, and bless each moment that we share. Our lives are the beginning of greater things, just one little notch in a very long string. Thank you for the blessings you give us each day, and help us to remember and show us the way. For our souls are in your mighty hands, we need your help to understand. As we move forward through this test lend us your strength and we'll do our best to keep our faith and understand, that we're all part of the greater plan.

S. Jenkins



Support Breast Cancer Research

Philanthropic gifts to support breast cancer research at the Indiana University Cancer Center are welcomed. Please contact Mary Maxwell at mmaxwell@iupui.edu, or by calling 1-800-643-6975 or (317) 274-3270.

Hot Flashes can be Annoying!

Janet Carpenter, PhD, RN

Hot flashes can be annoying for many women with breast cancer. Hot flashes begin as part of the natural aging process. They can also start after a woman stops hormone therapy, such as when her breast cancer is first found. Medications like chemotherapy and tamoxifen can also cause hot flashes. Research shows that hot flashes occur many times during the day and night and are often very intense and bothersome. They can disrupt a woman's 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.

What can you do about your hot flashes? The following tips can help you manage your hot flashes.

- Exercise in the morning when your body temperature is lower.
- Practice relaxation. Research shows that daily relaxation practice can decrease your hot flashes throughout the day and night.
- Learn about your hot flashes. Keep a daily journal of your hot flashes. See if you notice anything that makes them better or worse. Try to eliminate things that make your hot flashes worse. Alcohol and certain foods may trigger your hot flashes.
- Talk to your doctor or nurse about these medications: gabapentin, venlafaxine, and clonidine. These drugs do not contain estrogen. Women taking these drugs may have fewer and less severe hot flashes.

Investigators at the Indiana University Cancer Center are actively researching the hot flash problem. Recently, Dr. Bryan Schneider has shown that a minor genetic change (known as a polymorphism) in the hypoxia inducible factor 1 (HIF1) gene is associated with the likelihood of experiencing hot flashes. **This is the first time that a genetic change has been reported to affect the likelihood of experiencing hot flashes.** This implies that women may inherit a predisposition to experience them. This finding was made possible by working with the samples in our patient volunteer Friends for Life project. Dr. Schneider presented this research at the San Antonio Breast Cancer Symposium in December 2006.

Tamoxifen Update: New Revelations about an Old Friend

Doctors around the world use tamoxifen in the battle against breast cancer. This drug helps to lessen the chance of a breast cancer recurrence. It can also help prevent breast cancer in women who are at high risk for developing the disease.

Tamoxifen has other benefits and side effects. It might help prevent bone loss (osteoporosis) and heart disease. However, it can also cause hot flashes, vaginal dryness and other side effects related to the low estrogen levels seen in menopause.

Researchers at Indiana University Cancer Center have been studying women taking tamoxifen. A group led by David Flockhart , MD, PhD focuses on "pharmacogenetics," the study of how genes affect the way a person responds to a medication like tamoxifen. This group is linking a woman's genetic information with information on how her body breaks down the drug, the benefits she experiences, and severity of her side effects. As a result of this group's research, the United States Food and Drug Administration (FDA) now requires that certain warning labels are placed on tamoxifen prescription bottles. Their research is changing the way doctors use tamoxifen in the fight against breast cancer.

> Hot flashes!? We need breast cancer survivors who are having hot flashes to take part in a research study. The study involves 2 visits to the university scheduled one week apart and telephone interviews. By drinking a protein-like drink, answering questions, and having your blood drawn, you can help us better understand what causes hot flashes in breast cancer survivors. Participants will receive compensation for their time and effort. For more information, please call 317-278-6094, Jenny Milata, RN Project Manager, Indiana University School of Nursing.

Surviving and Thriving with Cancer: Tips for Enchanced Coping

by Shelley Johns, PsyD, HSPP

Virtually every treatment for breast cancer assaults what we, as women, hold dear: our femininity. Treatment for many women can seem like a "healing hell" that assaults one's femininity AND challenges one's coping skills.

Coping with cancer begins with the first suspicion of cancer—even before the first pathology report comes back—and it continues beyond treatment, for the rest of one's life.

Several factors that enhance one's ability to cope with cancer have been identified in research. These include being a person who:

- 1. tends to be optimistic, rather than someone who is pessimistic and feels helpless.
- 2. takes one day at a time rather than worrying constantly about the future or dwelling on mistakes of the past.
- 3. meets challenges head on, rather than coping with avoidance or denial.
- 4. is not prone to become highly stressed in the face of challenges.
- 5. has a strong fighting spirit and does not give up or fall prey to feelings of being overwhelmed.
- 6. sees the humorous side of negative things.
- 7. is informed about cancer, the goals of treatment, and its possible side effects.
- 8. works proactively with a supportive/reassuring/ communicative medical team.
- 9. has the type and amount of social support they desire, feels understood, and is not isolated.
- 10. has a philosophy of life that gives meaning to stressful life circumstances.
- 11. is generally "hardy"—believes they can exert some <u>control</u> over the events in their lives; has <u>confidence</u> that their strengths/resources will enable them to make things happen; is <u>committed</u>

to life, relationships, work, and living with purpose; and views stressors as *challenges* to be solved rather than as threats over which they are powerless.

- 12. minimizes the amount of time they spend criticizing themselves, or blaming/complaining about others and focuses their efforts on taking responsibility for enhancing their health and wellness.
- 13. seeks counseling to change behaviors or ways of coping or relating that are counter-productive.

After reading that list, you may be concerned that you don't land on the "positive" side of each of those factors. Few people do. Fortunately, your coping style affects how YOU behave, not how the cancer behaves...so you are not necessarily putting yourself at risk for recurrence just because you are worried or having a tough time coping. People who face their cancer with a sense of helplessness, hopelessness, fatalism, and avoidance are the ones who tend to cope less well.

If you fall into the "pessimistic" camp, or find it difficult to "hang in there" during the tough times, you can compensate by getting extra support (such as from your friends/family, your medical team, or another cancer survivor who has the kind of coping style you admire) or by learning some news ways to cope.

The IU Cancer Center offers a variety of free opportunities to enhance coping, from creative expression and music therapy, to spiritual support, massage therapy, appearance consultation, and social work consultation. For people who are striving to prevent or treat emotional distress, counselors with the IU Cancer Center CompleteLife program can help you to minimize distress while maximizing quality of life. Our therapists are skilled in assessing your current coping style and helping you to broaden your repertoire of coping strategies to enhance your sense of control and mastery as you seek to DEFEAT cancer. For more information or to schedule an appointment, please call (317) 278-6663.

ARE YOU INTERESTED IN LEARNING MORE ABOUT BREAST CANCER?

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