

IUSCC PINK



Dear Friends,

It is at a very young age that we recognize we are all unique and different. This recognition often results in taunting at the playground; a defense mechanism to point out others differences so that our own are minimized. Many go on to later embrace their uniqueness and some capitalize on it. For some reason, however, as scientists and doctors we have largely forgotten this basic tenant and have generally treated patients as if they are all identical. More recently, individualizing medicine has hit the mainstream with pharmacogenetics and is changing the way we think.

Pharmacogenetics is the study of how our own genetic make-up influences how drugs work. Our uniqueness is the result of differences identified within genes. Genes are the master blueprint which encodes everything about us (See Figure 1). It is what gives us different eye and hair color, and which makes

us different heights, etc. The most common genetic causes of differences are Single Nucleotide Polymorphisms, also known as SNPs (pronounced "SNIPS"). SNPs are subtle differences in the gene code which causes, in some cases, the formation of slightly altered proteins (the building blocks of our bodies) (See Figure 2 on page 2). These SNPs can be found within important proteins that metabolize drugs and in some of the targets that our anti-cancer drugs are trying to attack.

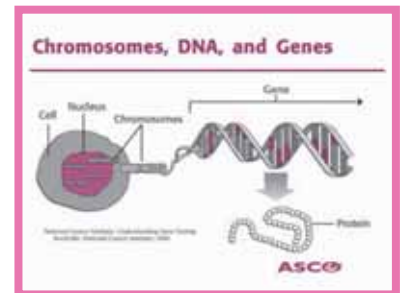


Figure 1

Studying these SNPs is an important part of research being conducted at IU School of Medicine. Recently our Clinical Pharmacology group identified a SNP which affects the rate of metabolism for tamoxifen. Tamoxifen is an important drug for the treatment of estrogen receptor-positive breast cancer. Tamoxifen is converted to the active ingredient within our liver by a protein called cytochrome P450 2D6 (often abbreviated "2D6"). SNPs within 2D6 can affect how well or poorly a woman forms the active ingredient which may ultimately affect who gets the most benefit (or side effect) from the drug. Also, importantly, many common drugs (including some of the anti-depressants such as Paxil and Prozac) affect 2D6; and therefore if taken along with tamoxifen can prevent the formation of the active ingredient. Current international studies will determine if testing for SNPs in 2D6 may be useful in deciding who should receive tamoxifen and who may gain benefit from another kind of hormonal therapy. While we currently don't

test for genetic variability in 2D6, it has already changed our prescribing pattern for anti-depressants. We no longer co-prescribe tamoxifen with anti-depressants that are potent blockers of 2D6.

"I may not be better than other people, but at least I'm different."

-Jean Jacques Rousseau

Another example of using genetic diversity to understand more about breast cancer has arisen from the "Friends for Life" project here at IU Simon Cancer Center. "Friends for Life" is a massive, volunteer-oriented project with the goal of collecting DNA (which houses all of the genes) and pertinent health related information **Continued on page 2**

Table of Contents

Pharmacogenetic: Individual medicine.....2	IUSCC Harmony to Healing.....2-3
The Effects of Breast Cancer on Intimac.....4	Breast Cancer Q & A.....5
Indy SurviveOars.....6	Avon Foundation Walk for Breast7

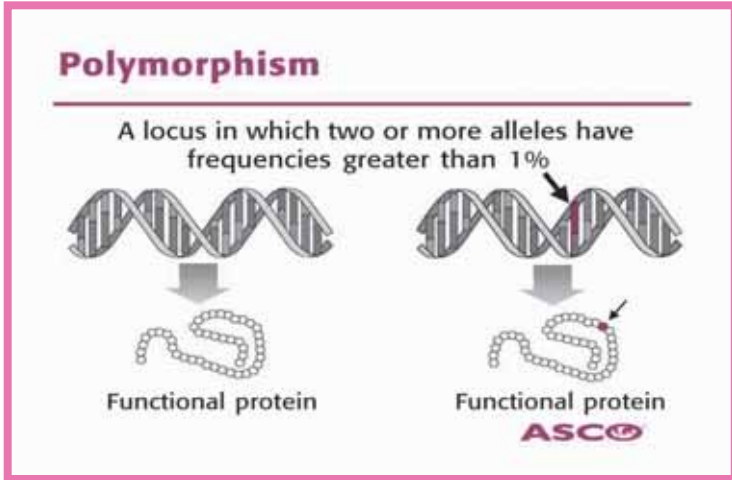


Figure 2

from a large group of women with breast cancer as well as from women who have never had breast cancer. This first recruitment effort was performed in association with the Komen Race for the Cure in Indianapolis in 2005. By comparing the genes within women who have had breast cancer to those who have not, we hope to identify SNPs that might be important in the biology of breast cancer. Thus far, we have identified two SNPs that appear to be important in the risk of breast cancer and one that also might protect against having hot flashes (an important problem for many survivors of breast cancer). Further studies are ongoing to confirm these findings. This project lives on as Mary Ellen's Tissue Bank where

other researchers can use similar samples for comparison in their breast cancer research. There are also several ongoing trials at IU Simon Cancer Center which are implementing this new science of pharmacogenetics (see table below).

Trial Name	Description
ELPh	This trial is evaluating two different aromatase inhibitors (therapies for estrogen receptor-positive breast cancer in post-menopausal women) in the context of several SNPs felt to be important in the activity of the drug.
Baby AC	This trial is evaluating the impact of SNPs on menstruation/fertility in pre-menopausal women receiving standard chemotherapy for breast cancer.
Center of Excellence	This trial is evaluating the impact of genetics on a variety of commonly used chemotherapies in women with advanced breast cancer.

While these are certainly the early days we hope to learn more about these SNPs and others to help improve our therapies; and perhaps in a more grandiose sense, possibly prevent the disease altogether some day. Only through continued research can we further understand how our own uniqueness affects how we will benefit from specific treatments. After decades of intense study and focus on the tumor, it is refreshing that we as scientists and physicians are re-learning principles that we learned as children; treat each person as the special individual she is.

-Bryan Schneider, MD

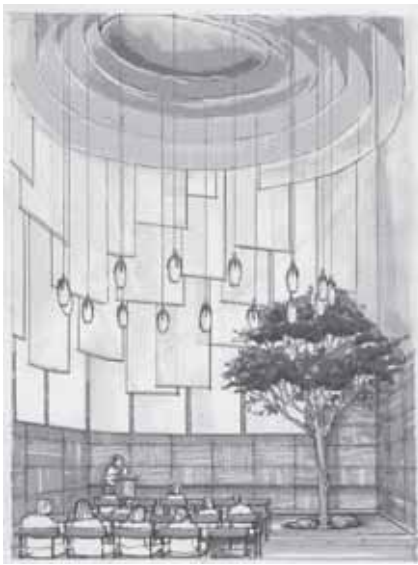
IU Simon Cancer Center Brings Harmony to Healing

The looming exterior of Indiana limestone and the spanning skywalk across West Michigan Street are evidence of the construction progress of the Indiana University Melvin and Bren Simon Cancer Center, opening fall of 2008. What lies behind those doors when they open in fall 2008 will be a serene natural environment, easily navigated by patient and families and uniquely functional for a seamless continuum of patient services.

Two years ago, focus teams collected the thoughts and desires of patients and caregivers specific to cancer care. Key inspirations gleaned from those discussions identified the power of nature as an affirmation of life, where light inspires hope and meditative space brings peace and nurturing.

Maregatti Interiors translates those inspirations into the building's design, bringing harmony to the healing process through a color palette reflecting the natural elements of earth, sky, wood, metal and water. Two tones of wood, teak and anigre, will be repeated through the building, as is the Indiana limestone cladding the building's exterior.

Upon entering the building, a 25-foot-high bamboo grove will flank the major passageway in the facility, reaching high enough to embrace a floating visitor's walk above. Rotating art or displays – from a carved metal mosaic to a small sitting niche -- keep the interior fresh, even for frequent or returning visitors. Healing gardens punctuating the



grounds and terraces of the IU Simon Cancer Center will provide a blend of the outdoors with the indoors.

Many amenities in the new building complement the interior architecture. Valet parking assists guests upon their arrival. Easy access is available from the main lobby to gift and sundries shopping, a retail pharmacy and a specialty boutique for cancer-related fittings, consultations and products. A public café offers healthy food choices for both the patient and the public. Complementary therapies

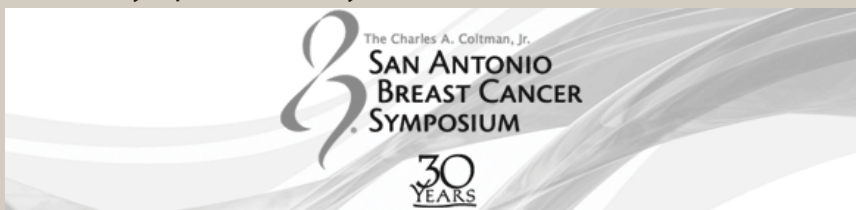
expand through IU Simon Cancer Center's CompleteLife program, offering appearance consultation, music and art activities, massage and relaxation counseling.

Balancing the interactive public areas are various intimate private spaces for professional consultation or personal reflection. Infusion areas for outpatient chemotherapy feature various comfort details, including fireplaces, expansive windows and privacy screens. Highlighting the inpatient floor will be such provisions as a family laundry room, family shower room and children's play area. All inpatient rooms will have boutique hotel sensibility with roomy private bathrooms, clothing cabinetry, small refrigerators and display shelves perfect for photos of loved ones or other inspirational items.

IU Simon Cancer Center will bring harmony to healing as part of its full, holistic spectrum of patient care services – from prevention through diagnosis and follow-up. For more information about the IU Simon Cancer Center a partnership between IU School of Medicine and Clarian Health, visit www.cancer.iu.edu or call 1- 888-600-4822.

Winter 2007/2008 Edition

We get many requests to hear about new research in breast cancer. Our next edition will answer those requests! The IUSCC Pink Winter 2007/2008 edition will focus on results from the 30th Annual San Antonio Breast Cancer Symposium. The SABCS provides state-of-the-art information on the experimental biology, etiology, prevention, diagnosis, and therapy of breast cancer and premalignant breast disease, to an international audience of academic and private physicians and researchers. We are very excited to share the results of this wonderful symposium with you!



Eating Well Through Cancer

By: Holly Clegg & Gerald Miletello, MD

Pumpkin Soup

½ cup finely chopped onion
½ teaspoon minced garlic
1 (15 oz) can solid pack pumpkin
3 ½ cup canned fat free chicken broth
½ cup skim milk
Salt and pepper to taste
Nonfat plain yogurt

Coat a pot with nonstick cooking spray, sauté the onion and garlic over medium heat until tender, about 5 minutes. Add the pumpkin. Gradually add the chicken broth and milk. Season with salt and pepper. Cook until heated through, about 5 minutes. Serve with a dollop of yogurt.

Makes Six (1-cup) servings: 45 calories each

This recipe is great paired with a sandwich for a light fall lunch. It is especially nice for those fighting neutropenia (a decrease in a type of white blood cell) caused by many chemotherapy drugs. Pumpkin soup is full of vitamin c, folacin and beta carotene. Also keep in mind that if you are trying to gain wait this recipe can be modified by using whole milk and regular yogurt.

As the days grow cooler try this recipe and let us know what you think!!



THE EFFECTS OF BREAST CANCER ON INTIMACY AND SEXUALITY

It is commonly recognized and discussed that a diagnosis of breast cancer is associated with emotional distress and changes in body image that affect how women feel about themselves. However, problems involving intimacy and sexuality that occur as a result of breast cancer and its treatments are not openly talked about even though they are commonly experienced. This makes them even more difficult to cope with.

Factors that affect sexual well-being and intimate relationships come from the emotional response to a diagnosis of cancer as well as from the treatment itself. Anxiety and depression decrease sexual desire or erase it altogether, while the fatigue, nausea, and pain that frequently come with surgery, chemotherapy, and radiation may at least temporarily make it seem that sex is gone forever.

It is also important to keep in mind that for women who are partnered, breast cancer is a couple's illness. Each individual in the relationship may be fearful of saying or doing something that might upset the other, while communication and sharing decline at the very time when they are needed most. While the breast cancer survivor lives with the physical and emotional experience of the disease, many partners feel their lives have been turned upside down, and fear of possible loss and uncertainty become frequent companions.

WHAT YOU CAN DO

What can you as a survivor and as a couple do to lessen these negative effects of breast cancer and its treatments on yourself and your partner? First, it is necessary to discuss problems you are experiencing related to sexuality with those who are providing your care. Let them know about your problems and concerns, and ask if there are any remedies they can recommend. Often doctors and nurses are hesitant to bring up sexual issues as they do not know if you would be comfortable talking about them, so **ask!**

Second, communication with your partner is **key!** A lack of sharing can result in each person imagining things that are far from true. For example, the breast cancer survivor may be thinking, "he just does not find me

desirable anymore," while a partner may be worrying about making "unfair demands," or may be fearful of causing physical or emotional pain.

Third, being sexual does not have to include intercourse. Do not pressure yourself and/or your partner with particular expectations. Benefit from each other's love and support, find time for each other, and don't minimize the importance of communication as these help develop and foster intimacy.

Fourth, it is helpful for each person in the relationship to have someone else other than the partner for sharing concerns. This is often more challenging for men than for women, but there are resources available. The American Cancer Society, as well as the medical team, can often make suggestions.

ON-GOING RESEARCH AND SUPPORT FOR COUPLES

There is currently a study for women and their partners who have received a diagnosis of breast cancer within the past year being conducted at the IU Simon Cancer Center. It involves three one-hour educational sessions with each couple, not in groups, concerning the problems of intimacy and sexuality that often follow breast cancer. These can either take place in person, or by telephone. If you are interested in further information, call Carol Decker at 1-800-433-0035.

-Betsy Fife, Ph.D., MSN

Featured Web site

The Ribbons of Pink Foundation has a simple Web site with a wonderful tool. This site has an awesome Breast Self Exam tracking tool. You can sign up to receive a monthly e-mail reminder to perform your BSE along with a chart to track any changes. Since October is Breast Cancer Awareness month, forward this Web site to all your friends so they too can be reminded that early detection is the most important factor in the fight against this disease!

www.ribbonsofpink.org



Breast Cancer Q & A

Q: Why do some spouses not want anything to do with your illness?

A: A cancer diagnosis is a very stressful event in one's life, and often worsens underlying tensions in relationships with our spouses, partners, and family members. Some spouses who weren't emotionally available or didn't pitch in before the diagnosis may retreat even further. It is important to know that some people may unconsciously withdraw as a way of protecting themselves from the pain of losing a loved one, or seeing a loved one go through tough treatments. Denial is an unconscious mechanism that makes us not want to accept that something bad is happening, and we then behave in that way. Communication is key in working out issues.

Q: Why is there an increase of new breast cancer?

A: Since 2002, the incidence of new breast cancer has in fact declined. Reasons for this are currently being studied, but it may be related to a drop in the use of postmenopausal hormone replacement therapy. Because of the increased compliance with mammogram and screening guidelines, we are detecting breast cancers when they are much smaller (less than ½ inch) and before they spread to the lymph nodes under the arm.

Q: What causes cancer?

A: Cancer in general is caused by a change (mutation) in the DNA of the milk duct cells within the breast. This change allows the cell to take on unique and undesirable features that include uncontrolled growth, ability to spread around the body, and the inability to die as normal cells would. Multiple different things likely contribute to this; many of which we don't currently know. Some that we do know include prolonged exposure to estrogen, family history of breast or ovarian cancer, exposure to high doses of radiation, and to a

lesser extent, lifestyle factors (e.g. tobacco use, alcohol use, and obesity).

Q: Why do you give choices of chemotherapy?

A: Chemotherapy is a generic term used to describe drugs that are used to treat cancer. Although many of these drugs work in a similar fashion by killing fast growth cells (cancer cells grow fast) we have learned that certain cancers are more susceptible to certain types/brands of chemotherapy agents.

Q: Is it ok to take blood pressure in the arm where I had lymph nodes removed?

A: The risk of chronic lymphedema after axillary (armpit) lymph node removal is about 5% lifetime. This is lymphedema that requires constant therapy to maintain control of the problem. Approximately 30% of women will develop lymphedema that responds to treatment with intervals between episodes of arm swelling; called transient lymphedema. If post-operative radiation therapy is required after axillary dissection the rate of chronic lymphedema increases to 30%. The causes of lymphedema are obscure and therapy is often directed at controlling symptoms rather than cure. Skin infections of the arm after axillary dissection have a high correlation with lymphedema. We therefore recommend that the patient minimize the risk of infection by avoiding invasive procedures like blood draws, intravenous infusions, and minor trauma to the skin like insect bites, burns and minor cuts. If any of these occur we recommend prompt treatment with topical antibiotics and dressings. Increases in arm pressure (barotrauma) can also increase the risk of lymphedema. This includes blood pressure cuffs and travel in compressed plane cabins. If you must fly we recommend a prophylactic compression sleeve.



When my sister had *breast cancer*, I felt helpless.
Now, I've found a way to make a difference.

~ a Sister Study participant

If you've never had breast cancer, but your sister has, join the Sister Study to help find the causes of breast cancer. Women who join are not asked to take any medicine, visit a medical center, or make any changes to their habits, diet, or daily life.
Woman by woman...Sister by sister...We can make a difference!

It's easy to join the Sister Study

Call: 1-877-4SISTER (1-877-474-7837, Toll-free) or 1-866-TTY-4SIS (Deaf/Hard of Hearing)

Visit: www.SisterStudy.org

Conducted by the National Institute of Environmental Health Sciences, one of the National Institutes of Health of the U.S. Department of Health and Human Services, with additional funding from NIH's National Center on Minority Health and Health Disparities.



Indy SurviveOars Glides into Metro Area



A new silhouette is emerging on the cancer survivorship horizon....and it's a dragon boat! Indy SurviveOars, a group of Indianapolis area breast cancer survivors, recently launched its organization to bring dragon boat racing to Indiana and create the first Indiana breast cancer survivor competitive team.

"Our mission is to help provide breast cancer survivors with a strong message of hope, inspiration and encouragement," Lisa Heiden Peters, president of Indy SurviveOars, describes. "We are creating a 'floating support group.'"

Dragon boat racing began more than 1,500 years ago in China and eventually made its way to North America in the 1980's. Now the fastest growing team sport in the world, it features sleek, slender boats decorated with dragon heads and propelled by 20 paddlers working in unison. The drummer beats out the pace, while a steer person guides the 48-foot-long-boat on its course.

Don McKenzie, MD, a sports medicine physician at the University of British Columbia, launched Abreast in a Boat in 1996 to test the myth that repetitive upper body exercise in women treated for breast cancer encourages lymphedema. He believed that following a special exercise and training program would not increase the risk, but would actually improve quality of life.

Dr. McKenzie's theory proved correct. Since 1996, hundreds of breast cancer survivors across the world have formed dragon boat teams, and are paddling and racing

regularly, promoting good health and fun. An emerging body of research suggests that the physical activity not only has a positive effect on quality of life following a diagnosis of cancer, but may also improve survival.

The Indianapolis team is deemed to be the 50th such team in the United States. Recognizing this unique activity for building physical wellness and psychological well-being, the Indiana University Melvin and Bren Simon Cancer Center and Clarian Health have pledged a three-year commitment to the program as Premier Sponsor.

The pledge provides the resources to order the boat from a manufacturing company located in China. Decoration of the boat will be finalized locally, with a formal launch at Geist Marina expected in spring 2008.



A pool of at least 50 breast cancer survivors are needed locally to train, to ensure that a full boat of participants is always available, Heiden Peters explains. Additional participants are needed to help train with the survivors.

Visit www.indysurviveoars.org for registration or more information.

Lymphedema Research at IUSCC

The Indiana University Breast Care and Research Team is currently studying the effects of an anti-angiogenic drug, Avastin, on lymphedema. If you have lymphedema in one arm as a result of your breast cancer surgery and are not receiving active treatment (Radiation or Chemotherapy) you may be eligible. Contact Casey Allen at 317-274-0594 for more information.

The Avon Foundation Walk for Breast Cancer



Mandi Garner-Center with fellow walkers

The Avon Walk for Breast Cancer is a two-day walk that covers more than 36 miles. This year, there were 3,600 people who participated in the Chicago walk and a total of \$8.3 million was raised. The money goes toward helping five different areas of breast cancer: awareness and education, screening and diagnosis, access to treatment, support services and scientific research. All of these areas are focused on the medically underserved.

This was my second year to complete the Avon Walk for Breast Cancer. Last year, it was just me and one other friend and this year there were three of us. Each one of us had to raise at least \$1,800 to do the walk and together we raised more than \$5600.00. We raised this money by donations, selling candles and a golf outing in Anderson at Meadowbrook Golf Course.

The day of the walk, we started at Soldier Field. The first day, we walked 26.2 miles. We had port-a-potties and drinks available every two miles. Every other stop, snacks were available. We were definitely taken care of! Unfortunately, one of the girls I walked with had to stop after 22 miles due to blisters that looked terribly painful.

When we got to the end of the first day, we had to find our luggage and pitch our tents. After eating dinner, we were off to the "Port-a-cleanse." This was pretty much how it sounds, a big semi with showers in the back of them. Then we were off to the tents for sleep. With so many tents so close together, we could hear people snoring, and like school girls, couldn't stop laughing and cracking jokes.

When we woke up the second day, we packed up our tents, loaded the luggage, ate breakfast and then off we were off for another 13.1 miles!

Many people ask me why I chose to participate in this walk when it is so long, I am sore for days afterward, and I have to raise so much money. I have a simple answer. I am an oncology nurse who gives chemo treatments everyday. I have no family history of breast cancer, but I have met many people who have been diagnosed with breast cancer who had no family history. I have also formed a close relationship with many of the women that I have given treatment to. Every time my feet started to hurt during the walk, I would think of them.



-Mandi Garner RN

For more information about the Avon Foundation Breast Cancer Walk visit walk.avonfoundation.org or e-mail Mandi at mandistrong@excite.com if you are interested in participating or want to help her raise money for next year's event (Chicago May 31-June 1, 2008).

Upcoming Events

October is Breast Cancer Awareness Month so there are lots of great events. Here are a few!!

October 6th Making Strides Against Breast Cancer-South Bend & Fort Wayne, IN (www.cancer.org)

October 7th Creating Hope Walk-Fishers, IN (creating-hope.org)

October 13th Y-ME Fashion Show Luncheon-Indianapolis, IN (www.y-me.org/indiana)

October 14th Making Strides Against Breast Cancer-Merrillville, IN (www.cancer.org)

October 15th YSC Courage Night-Indianapolis, IN (www.youngsurvival.org/en/indianapolis)

October 20th Making Strides Against Breast Cancer-Indianapolis, IN (www.cancer.org)

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:

IU Simon Cancer Center
535 Barnhill Drive, RT 473
Indianapolis, IN 46202

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/>).