IUCC PINK

Volume 1, Issue 1
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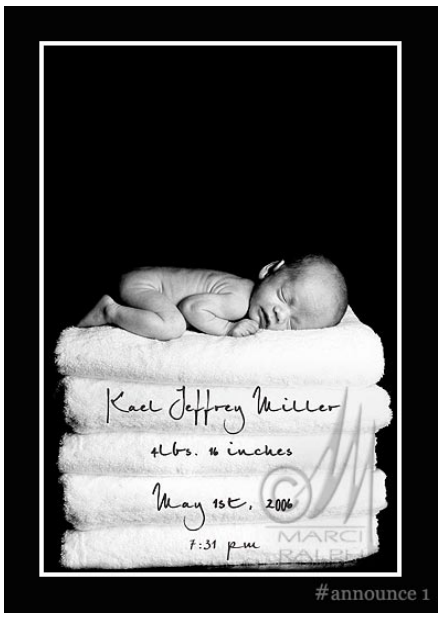
Announcements

Announcing the arrival of
Kael Jeffrey Miller
Proud parents are Drs. Kathy and Jeffrey Miller



Kael is the cutest and smallest member of the IUCC Breast Cancer Program.

Dear Friends:

This is the first edition of what we hope will be an ongoing newsletter of the Indiana University Breast Cancer Program for our patients, their families, as well as others interested in the fight against breast cancer. The Indiana University Breast Cancer Program is part of the larger Indiana University Cancer Center (IUCC), a National Cancer Institute-designated cancer center that performs research as well as provides clinical care and education.

Dr. George Sledge visiting with breast cancer survivor Lynn Haughey.

At Indiana University we believe that breast cancer requires the combined efforts of a dedicated group of physicians and allied health care personnel focused on the breast cancer problem. We have devoted much of the past two decades putting together a clinical team that rivals any breast cancer group in the nation for cutting edge breast cancer care. We will introduce members of our team to you with special expertise in your areas of concern and interest.

We also believe that the cure for breast cancer is research. We have, as a society, made great strides in the treatment of breast cancer in recent years. This progress resulted from the efforts of laboratory scientists, clinical researchers, and patient volunteers. The IU Breast Cancer Program has put together a talented team of laboratory and clinical investigators to study the biology and treatment of breast cancer. In recent years this team has had some stunning accomplishments that have altered the way we treat breast cancer.

Our newsletter will share our thoughts both on how breast cancer is diagnosed and treated, and how we are developing new treatments for the disease. Our goal, working with our patients, is to render this frightening diagnosis less frightening. We'll try and present you with useful information about the disease, with links to other web sites that have tackled many of the questions patients find troubling or confusing. We will also share with you the insights we've gained about the disease, as well as our patient's insights. We will also bring you up to date on new research developments, especially new clinical trials that offer our patients a chance to benefit from some of the encouraging new therapies being developed.

George W. Sledge, Jr., M.D.

What is a Clinical Trial?

A clinical trial is a research study in human volunteers to answer specific health questions. Carefully conducted clinical trials are the safest and fastest way to find treatments that work in people, and new ways to improve health.

Many clinical trials are done to see if a new drug or device is safe and effective for people to use. Clinical trials are also done for other reasons. Some compare existing treatments to determine which is better. Sometimes clinical trials are used to study different ways to use the standard treatments so they will be more effective, easier to use, and/or decrease side effects. There are clinical trials that study prevention options, new screening and diagnostic techniques and options for improving the quality of life for people who have serious medical conditions. Sometimes, studies are done to learn how to best use the treatment in a different population, such as children, in whom the treatment was not previously tested.

Clinical trials are conducted according to a plan called a protocol. The protocol describes what types of patients may enter the study, schedules of tests and procedures, drugs, dosages, and length of study, as well as the outcomes that will be measured. Each person participating in the study must agree to the rules set out by the protocol.

Clinical trials are usually conducted in a series of steps, called phases. Patients may be eligible for different phases, depending on the type and stage of their cancer, pervious treatments, and their overall general health.

Phase I trials:

Phase I trials are the first step in testing a new approach in people. In these studies, researchers evaluate what dose is safe, how a new agent should be given (by mouth, injected into a vein, or injected into the muscle), and how often. Researchers watch closely for any harmful side effects. Phase I trials usually enroll a small number of patients and take place at only a few locations. The dose of the new therapy or technique is increased a little at a time. The highest dose with an acceptable level of side effects is determined to be appropriate for further testing.

Phase II trials:

Phase II trials study the safety and effectiveness of an agent or intervention, and evaluate how it affects the human body. Phase II studies usually focus on a particular type of cancer, and include fewer than 100 patients.

Phase III trials:

Phase III trials compare a new agent or intervention (or new use of a standard one) with the current standard therapy. Participants are randomly assigned to the standard group or the new group, usually by computer. This method, called randomization, helps to avoid bias and ensures that human choices or other factors do not affect the study's results. In most cases, studies move into phase III testing only after they have shown promise in phases I and II. Phase III trials often include large numbers of people across the country.

Phase IV trials:

Phase IV trials are conducted to further evaluate the long-term safety and effectiveness of a treatment. They usually take place after the treatment has been approved for standard use. Several hundred to several thousand people may take part in a phase IV study. These studies are less common than phase I, II, or III trials.

Source: National Cancer Institute (NCI) and Federal Drug Administration (FDA)

For more information on clinical trials visit:
www.cancer.gov/cancertopics/factsheet/Information/clinical-trials or
http://cancerweb.ncl.ac.uk/cancernet/203900.html

The physicians at the Indiana University Cancer Center Breast Program and their staff are dedicated to helping advance healthcare for breast cancer patients. They are leaders in clinical research and are currently conducting cutting-edge clinical trials for breast cancer patients. Please feel free to talk to any of the physicians or staff about participating in a clinical trial.

Our breast cancer medical oncologists are Dr. George Sledge, Jr., Dr. Kathy Miller, Dr. Anna Maria Storniolo, Dr. Bryan Schneider and Dr. Daniela Matei. Our research nurses include Anita Rush-Taylor, Darlene Christmon, Danielle Latinovich, and Cheri West.

I was too Young to have Breast Cancer!

A story of inspiraton and courage by Alison Chestovich.

It was a cyst. I showed the lump to my family doctor and was assured that the lump was a cyst; perfectly normal and nothing to worry about. For nearly two years she told me that, and under my fingers (and hers) the lump grew from the size of a pea to the size of a jawbreaker. With each exam she repeated the same words: I was too young for cancer and the lump was a cyst. That I had no family history and the lump was a cyst. I was a non-smoker, an infrequent drinker, a regular exerciser, of a healthy weight, and the lump was a cyst. But always, always, that I was too young. And always, always, that the lump was a cyst.

You know how the story goes. The cyst wasn't a cyst. And I wasn't too young for cancer.

I was one day away from turning 29, and I had breast cancer. In another life I had a dream job at a downtown law firm, a new house, and a newer boyfriend. I was training for a marathon, and had recently gone trekking in the Himalayas. I was young, strong, and healthy. All that changed with the cyst that wasn't a cyst.

A new life began. A new life as a cancer patient. I was terrified. I knew I would lose my hair. Would I lose my breasts? My job? My house? What would my body look like? Would I lose my boyfriend? (And, the unspoken question: would I die?) The doctor who had let my life tick away under her fingertips was not an Indiana University doctor. The doctors who intervened, and who saved my life, were. Their names are Dr. Robert Goulet, Jr. and Dr. Kathy Miller. Our journey began when they said the words I least wanted to hear: "it's cancer." The shock and horror of hearing that news was followed by chemo, surgery, more surgery, more chemo, and thirty-odd radiation treatments. I did lose my hair — headscarves and bandanas were my "new black." Flights of stairs were suddenly as daunting as the Himalayan trail had been. I found myself using all of my powers of concentration to finish a bowl of soup. And, perhaps the greatest challenge of all - my mother moved in to take care of me. (I'm still trying to figure out where she put everything in my kitchen.) But, all the same, I was lucky. I kept my breasts, my job, and my house. My body looks much the same as it did. I lost my boyfriend, but have since gained another (yes, honey, "better.") But, most importantly, I kept my life. I survived, thanks to the care I received at the IU Cancer Center.

Through it all, I was never alone. I had my family and friends for support, of course, but family and friends, in spite of their good intentions, could only do so much. At IU, not only were my questions answered, but I found a place where I could take my brave face off for a bit. I found comfort and solace in the simple truth that the people at the Cancer Center had seen it all before. There, I could joke, or I could cry, and I did both regularly. I could be scared, elated, or pissed off, or any one of the other thousand emotions that ran through me on any given day. And, through IU, I found other survivors. Their experiences too closely resembled my own, and we could be scared, elated, or pissed off together. The cancer is gone, but the sisterhood I found remains.

Friends and acquaintances who watched my battle tell me that I'm an inspiration. I don't feel like an inspiration. I simply did what I was told, dealt with the treatments as best I could, and sat back and watched as my body responded.

Continued

I was too Young, Continued from page 3

Because of the research that has been done on breast cancer in the past few decades and especially in the past few years, my doctors were better able to pinpoint the treatments I needed based on the cancer I had.

The people who went before me are the real inspiration. Their paths were not so sure as mine because the research had not yet been done, and they made possible the treatments that saved my life. In their honor, and in honor of the women and men who I know will follow me, when I was given the opportunity I participated in two clinical trials at IU. Each trial required very little of me other than a bit of time. I know I owe my life to the work that is done at IU and at other institutions like it, and I was glad to be given the opportunity to have some small part in furthering that research.

Alison after completing treatment. Alison believes that, "The people who went before me are the real inspiration. Their paths were not so sure as mine because the research had not yet been done, and they made possible the treatments that saved my life."

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.

IUCC Pink Dictionary

Adjuvant Therapy: Treatment given after the primary treatment to increase the chances of a cure. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, or biological therapy.

Breast Cancer: Cancer that forms in tissues of the breast, usually the ducts (tubes that carry milk to the nipple) and lobules (glands that make milk). It occurs in both men and women, although male breast cancer is rare.

Chemotherapy: Treatment with drugs that kill cancer cells.

Metastasis: The spread of cancer from one part of the body to another. A tumor formed by cells that have spread is called a "metastatic tumor" or a "metastasis." The metastatic tumor contains cells that are like those in the original (primary) tumor. The plural form of metastasis is metastases (meh-TAS-ta-seez).

Neoadjuvant Therapy: Treatment given before the primary treatment. Examples of neoadjuvant therapy include chemotherapy, radiation therapy, and hormone therapy.

Palliative Treatment: Treatment given to relieve the symptoms and reduce the suffering caused by cancer and other life-threatening diseases. Palliative cancer therapies are given together with other cancer treatments, from the time of diagnosis, through treatment, survivorship, recurrent or advanced disease, and at the end of life.

Radiation Therapy: The use of high-energy radiation from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors. Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy, implant radiation, or brachytherapy). Systemic radiation therapy uses a radioactive substance, such as a radiolabeled monoclonal antibody, that circulates throughout the body. Also called radiotherapy.

Source: National Cancer Institute

Hormone Receptor Status

What Does it Mean to 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 your breast cancer you and your doctor can make better decisions about your treatment.

A characteristic of breast cancer that is important to know is hormone receptor status. Some breast cancer cells have receptors that are sensitive to the hormones estrogen (ER) and/or progesterone (PR). When the receptors are stimulated by ER and/or PR they send signals to the cell to divide and grow. You can think of the hormones as 'feeding' the cancer cell so that it can grow more rapidly. If the cancer cells have a high proportion of ER and/or PR receptors they will be very sensitive to those hormones and they will grow more rapidly. A low proportion, or no ER/PR receptors, means that the cancer cells have very little, if any, sensitivity to ER and/or PR. The more ER/PR receptors a cancer cell has the more it is 'fed' by these hormones.

The hormone receptor status of a tumor will determine if you are a candidate for hormone therapy. A tumor with cells that have many estrogen and/or progesterone receptors, it is called ER or PR positive. A tumor with cells that have very few or no ER or PR receptors, is call ER or PR negative. A patient with an ER and/or PR positive tumor is a candidate for hormone therapy. The term hormone therapy may seem confusing. If hormones are causing the tumor to grow faster, why give hormone therapy? Actually a more accurate term would be anti-estrogen therapy; however, this form of treatment for breast cancer began being referred to as hormone therapy, and it is the term that is used today.

Presently there are two forms of hormone therapy. The drug tamoxifen works by finding and occupying, or sitting on, the estrogen receptor. When the estrogen receptor is blocked estrogen cannot stimulate the cell to grow. The other hormone treatment for women who are postmenopausal is called an aromatase inhibitor (AI). After menopause, estrogen is produced by the adrenal glands. There is a long series of chemical changes that happen before the actual estrogen is produced. One of the steps in the process needs the enzyme aromatase to work. The aromatase inhibitor blocks aromatase and estrogen is not produced. If there is less estrogen in a woman's body, the ER receptors are not stimulated.

The hormone receptor status of a breast cancer tumor can be found on the pathology report that is done after a biopsy or surgery. 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

Sample Surgical Pathology Report

Name: XXXXXXX
DOB: XXXXXXX
Submitting Physician: XXXXXXXXXX

Clinical Information:
The patient is a 49 year old female.

Specimen Received:
Right Breast, needle biopsy

Final Pathologic Diagnosis:
Right Breast, needle biopsy
Infiltrative dictal carcinoma, SBR socre of 7
2.4 mm in largest dimension in the needle core tissue
Tumor is ER-negative, PR-negative
HER-2/neu negative
Oncoprotein-negative

Friends for Life
and
Mary Ellen's Tissue Bank

The use of tissue specimens in research is vital for medical science to advance. We are now in the age of understanding how normal cells and cancerous cells actually work. Research using tissue is essential to understand the causes of cancer, identify targets for treatment, discover biomarkers that can identify characteristics of a cancer and develop treatments that target a specific gene or signaling process. Having non-malignant tissue available for research is critical to the understanding of "normal" cellular processes, and as controls for comparison in the study of malignant transformation.

Santosh Philips, a research anaylsis at IU

Mary Ellen's Tissue Bank is directed by Dr. Anna Maria Storniolo and within Indiana University Cancer Center's Catherine Peachey Breast Cancer Prevention Program. This tissue bank will store a variety of "tissue" samples (breast tissue, saliva, blood, etc), as well as clinical information about the person who donated the specimen. This "annotation" will allow researchers to "marry" clinical facts about family history, personal health history, etc. to the biological and molecular information derived from the tissue analysis.

Dr. Anna Maria Storniolo and Dr. Bryan Schneider

One major enhancement to Mary Ellen's Tissue Bank has been the Friends for Life project. This initiative, led by Dr. Bryan Schneider from the IU Cancer Center, is an event that coincideds with the Indianapolis Race for the Cure (with the permission of the Komen Foundation) over the last two years. The Friends for Life study was made possible by the assembling of an amazing group of over 200 volunteers, coordinated and led by Suzanne Lemler, RN, of the IU School of Medicine's division of clinical pharmacology. Suzanne's drive and creativity were critical in making this unique effort a reality. The contributions of this group have made possible the collection of blood samples from approximately 2000 women to date. This massive undertaking included obtaining an informed consent, a blood sample, and a questionnaire that included risk factors for breast cancer of study participants. The collection of 2000 samples in such a short time has been an invaluable resource, and the first effort of this kind.

(from left to right) Connie Rufenbarger, Catherine Peachey Foundation Advocate, Dr. David Flockhart, Directer of Clinical Pharmacology, Suzanne Lemler, RN, Nursing Coordinator Clinical Pharmacology.

The primary goal of Friends for Life has been to identify genetic and protein differences between women with and without breast cancer. The hope is that these differences might point to important genes or proteins involved in the cancer process. By understanding these differences, investigators might later learn how to identify who is at risk and possibly even use that information ultimately to combat breast cancer. One critical element of Friends for Life is that women were given the opportunity to donate their blood sample and medical history information to "other research." Those samples have now become part of the Mary Ellen's Tissue Bank for other breast cancer researchers to use in the future.

Friends for Life, Continued from page 6

2006 Friends for Life Volunteers

A great big "THANK YOU" to our Friends for Life! With the help of over 200 volunteers, we have collected almost 2,000 blood samples to be used for breast cancer research. The special undertaking was and is possible only because of the generosity and hard work of all of our volunteers as well as the breast cancer survivors and the many other women who donated a small amount of their blood towards the cause of making breast cancer a thing of the past!!!! Thank you sincerely.

Because of the success of our initial Friends for Life we plan to continue collecting samples. All future specimens collected at our "Friends for Life" events will be directly deposited in Mary Ellen's Tissue Bank for multiple breast cancer researchers to explore.

IUCC Resource Center

Helpful Websites

breastcancer.org
A nonprofit organization for breast cancer education.

www.researchadvocacy.org
Research Advocacy Network Advancing Patient-Focused Research

www.lbbc.org
Living Beyond Breast Cancer

www.komen.org
Susan G. Komen Breast Cancer Foundation

www.y-me.org
Y-ME National Breast Cancer Coalition

www.cancer.gov
National Cancer Institute

Upcoming Events

Camp Bluebird
Weekend Retreat for Adult Cancer Patients and Survivors.
Fall Retreat dates are September 29, 30 and October 1, 2006.
Contact Kathy Stolz at 317-962-2207 or kstolz@clarian.org

American Cancer Society
Making Strides against Breast Cancer 5K Walk
October 21, 2006
Contact Kristen Scott at 317-280-6603 ext. 6635

Y-Me 12th Annual Fashion Show and Luncheon
October 14, 2006
Indianapolis Downtown Marriott
Contact the Y-Me office at 317-844-6017

October is National Breast Cancer Awareness Month

ARE YOU INTERESTED IN LEARNING MORE ABOUT BREAST CANCER?

What topics are you interested in learning more about?

_____
_____
_____

Would you like to share your experiences in the *IUCC Pink* Newsletter? Yes ____ No ____

Sign up to receive the *IUCC Pink* Newsletter

Name: _____

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E-mail* _____

*Newsletters will be sent by email when applicable.

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535 Barnhill Drive, RT 473
Indianapolis, IN 46202
Or send an email to dkputt@iupui.edu to add your name.

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