

CAROLINA
BREAST
CANCER
STUDY

CBCS Newsletter

For Study Participants

Phase III: The Jeanne Hopkins Lucas Study

An epidemiologic population-based breast cancer research study at the University of North Carolina-Chapel Hill Lineberger Comprehensive Cancer Center funded through the University Cancer Research Fund and the National Cancer Institute

"Beauty, grace, strength, and persistence..."

Follow-Up Issue #1

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Study Contact Information

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CB # 7294
Chapel Hill, NC 27599-7294

Phone: 1-866-927-6920 or
Email: cbcs@unc.edu
<http://cbcs.med.unc.edu/>



Thank you! From all of us at the Carolina Breast Cancer Study (CBCS), I want to express my deep thanks to you for taking part in our study. You are a member of one of the largest studies of breast cancer ever undertaken, and one of the first studies to include younger women, African American women, and women from the rural South. We could not do the study without you. Your participation is very

important!

I want to take a minute to tell you a little more about our study, and the role that breast cancer patient advocates play in making our study a success. For over 20 years we have known that breast cancer mortality is higher in African American women and younger women. Using data collected from CBCS between 1993 and 2001, we found younger women and African American women have higher rates of basal-like breast cancer. Basal-like breast cancer is a form of triple negative breast cancer (ER-negative, PR-negative, HER2-negative).

In order to better understand the causes of basal-like breast cancer in African American and white women, we are enrolling an additional 3000 breast cancer patients in our study. That's where you come in. Your participation, the stories you tell us, and the information you provide to us are so important. Without you, we would never be able to understand the causes of breast cancer in North Carolina, or how to prevent it.

Since the very beginning, breast cancer patient advocates have played a strong role in the CBCS. Since 1993, local breast cancer survivors meet with our staff to develop outreach materials, informed consent documents, questionnaires, and other study materials. Advocates help write summaries of our research findings to share with the public. Most importantly, advocate input and assistance with community outreach have produced response rates for our study that are among the highest ever recorded for population-based studies of breast cancer.

I hope that you will continue to take part in the follow-up interviews for our study. We want to stay in touch with you, hear about your experiences, and we want you to share with us any obstacles that you encounter in obtaining quality health care. This is a big part of our research. Thank you again for all that you do for our study and for the people of North Carolina!

Sincerely,

Robert Millikan

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Recruitment Progress. By June 2013, 3000 women will be enrolled. Our ginkgo sapling has grown into a beautiful, full-grown ginkgo tree. Thanks for your participation!



The Resource Navigation Unit

Finding breast cancer resources that suit your specific needs can be a very frustrating thing—especially if you don't know where to look. Know this: you are not alone! Available to all of our participants, a Resource Navigation Unit has been formed by the CBCS staff to help you find the resources you need within your local community.

Many CBCS participants have contacted us expressing their need for a number of different resources. Whether you are looking for financial support, insurance information, survivor support groups, a wig, or prosthesis, the Resource Navigation Unit

will get you connected to the organizations and assistance programs that can help.

If you prefer to do the research on your own, the Breast Cancer Resource Directory of North Carolina, 4th Edition, is an invaluable “one-stop” support tool for those with questions about diagnosis, treatment, locations for support, and financial assistance in all counties of North Carolina. It provides North Carolinian breast cancer patients, survivors, their families, friends and healthcare providers with free, comprehensive information and a variety of options for treatment and support. Additionally, complete Directory

information, with downloadable PDF files of individual chapters, is now available online (<http://bcresourcedirectory.org>).

If you need help and don't know where to turn, call our toll-free number, 1-866-927-6920, to contact someone in the CBCS Resource Navigation Unit or to request a copy of the Breast Cancer Resource Directory by mail. Please leave your name and a telephone number, and we'll be glad to return your call.

The Sisters Network and CBCS Unite to Fight Breast Cancer

The Sisters Network Inc. is the only national African American breast cancer survivorship organization in the U.S., with a current national membership of over 3,000 among 40 affiliate chapters. The Sisters Network has already helped over 6.8 million families affected by breast cancer.

In 2003, six breast cancer survivors wanted to raise awareness in NC about the devastating impact that breast cancer has on the African American population. So, they formed the Sisters Network Triangle, an NC affiliate. Now, with over 50 members, they provide community education and outreach to thousands of NC women annually. They host numerous events including symposia, Tea for Two Pink Ribbon Campaign, Gift for Life Block Walk, and the Check, Detect and Protect



Members of the Sisters Network Triangle

Program. Furthermore, they were named Outstanding Chapter by the national organization in 2003.

The Sisters Network Triangle has joined forces with CBCS to assist with the study. Their members have served as mentors and advisors regarding effective communication and outreach to CBCS's African-American participants. Together, we hope to bring to light the importance of improving cancer outcomes for this population.

To learn more about Sisters Network Inc., make a donation, or join a local chapter, visit: www.sistersnetworkinc.org

For more information or to join the Sisters Network Triangle, based out of Durham, NC contact:
Valarie C. Worthy (President)
Phone: 919-490-1571
E-mail: sisterstriangle@aol.com

SURVIVOR *Diaries*

This section of the CBCS newsletter includes participants' stories of inspiration, strength, and survival. We hope it serves as a means of support and education to anyone affected by this disease.

If you'd like to submit your own story and photo...

Mail to: Carolina Breast Cancer Study
UNC-Chapel Hill, LCCC
Attn: Survivor Diaries, Rm 332
CB # 7294
Chapel Hill, NC 27599-7294
or E-mail: cbc@unc.edu

Faith and Hope

Submitted by R.M., Pitt County, NC:

The day I was diagnosed with cancer, it gave me a shock. I had just lost a sister to that "monster" a few months before I was diagnosed with it. I shed a few tears, not knowing what to expect after seeing all the things my sister went through.

I caught a hold of myself with my faith in God knowing what He had promised me. If I would trust Him and believe in what His Word says, God would take me by the hand and walk me through it. And that is what He did.

So, in the meantime, while I am waiting on my total healing, I have decided to keep a positive attitude, be joyful, keep my smile, and live my life to the fullest in helping others to live. I'm participating in the Carolina Breast Cancer Study hoping that down the line, they will find the total cure and better the life of someone else.



Project Survive and Thrive

Submitted by C.A., Alamance County, NC:

A short while ago, I attended Project LEAD, a breast cancer advocacy conference in La Jolla, CA. On the overcrowded flight there, I began a conversation with the gentleman seated next to me. Indeed, he was how I thought a native Californian should look with a bronzed tan, blond hair, intense blue eyes, and a casual manner with his dress and poise. He was a picture of health for a retired school teacher who had taught middle school for 35 years.

We easily conversed about countless things. However, upon telling him the purpose of my trip and that I was a 17-year breast cancer survivor, his casual manner suddenly disappeared. I wondered if I had offended him by talking about cancer. But after a long and thoughtful moment, he leaned over and whis-

pered he had just completed treatment for prostate cancer.

"I've never discussed my cancer with anyone but my doctor," he admitted. After suggesting that we talk about it, the man finally opened up to me with a number of questions, including why his cancer had formed. "It was nothing you purposely did to develop cancer," I said. "That's what researchers are doing now. Trying to find a cure—to figure out what happens inside that cell to make it multiply and grow abnormally." Although my words were meant to comfort, I only saw fear in his eyes. He was scared the cancer would return. I could only say, "Even though there's a possibility it may come back, you still thrive. That is what makes you a Survivor!"

To get over my own fear of recurrence, I made a list I've called "Gunna Do's Before I Die." My long

list isn't comprised of large or expensive things either, it's made up of all the little things I've always wanted to do but have put off because of silly excuses. For the past 17 years now, I've been checking off each thing I've accomplished. Occasionally, I'll even add something new. In fact, one of the things on my list was to stick my feet into the Pacific Ocean. When I was in La Jolla, I made it happen!

So, you see, we all should do everything in our power to make our lives worth living. Otherwise, we might as well be dead. There's no sense living in fear. Although there are a lot of things we can't prevent from happening, there are a lot of things that we can make happen ourselves. I once heard that life is not a dress rehearsal, it's the real thing, and we've got to show the world everything we've got!

Robert Millikan
DVM, PhD
Principal
Investigator
(right)



Mary Beth Bell
Project Manager
(left)



Georgette Regan
(left)
Lena Ehret
(right)
Nurse
Interviewers



Dana Renn-Reep
(left)
Sue Campbell
(right)
Medical Records
Abstractors



Sara Williams
Research
Assistant
(above)

CBCS Spotlight

Catherine "Cat" Andrews



Sasha McGee
Graduate
Research
Assistant
(right)



Michele Smith
Research
Assistant
(left)



What Cat Does: Cat is CBCS's Follow-Up Research Assistant. She phones study participants to obtain updated treatment and lifestyle information.

Cat's Story: In 1992, Cat was diagnosed with breast cancer. After enduring a year of surgery, radiation, and chemotherapy, Cat became a breast cancer advocate as soon as her strength returned. She joined other survivors in the fight against the disease by spreading awareness and education. Since then, Cat has lobbied in Washington, DC with the National Breast Cancer Coalition to keep cancer research funds available. She then became a founding member of the Breast Cancer Coalition of NC in 1993, with goals to educate, advocate, and obtain better care and treatment for the women of NC. She performed in the dark-comedy musical, "Breast Taking," which portrays the different points of view of everyone affected by breast cancer. In 2001, Cat became a recruiter for the Sister Study, a national investigation examining the environmental factors that may affect women who develop breast cancer. She has served on the NC Cancer Control Committee (2003), which was formed by the governor to encourage physicians, researchers, and survivors to work together in the fight against cancer in NC. Recently, Cat was honored as a Foot Soldier for the Dr. Susan Love Research Foundation Army of Women. One day, Cat hopes to write an autobiography of her journey and triumph over breast cancer to help support and inspire others.



Nicholas Taylor
Graduate
Research
Assistant
(above)



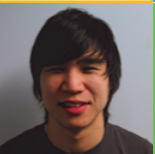
Roxan Brock
(above)
Lisa Lacks
(below)
Nurse
Interviewers



Riza Bueser
Research
Assistant
(above)



Judy Bryan
(left)
Pamela Mack
(below)
Research
Assistants



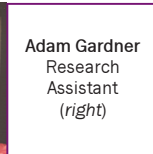
Scott Gee
Research
Assistant
(left)



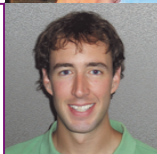
Leila Family (left)
Peter Samai
(right)
Graduate
Research
Assistants



Nicole Caviness
Research
Assistant
(right)



Adam Gardner
Research
Assistant
(right)



Your 9 Month Follow-Ups: What to Expect

Every nine months or so for the next two years, someone from CBCS will be contacting you to obtain more information about additional chemotherapy and/or radiation treatments, additional surgery or biopsy procedures, and other physician visits you may have had since we last spoke with you. We will also be asking some questions about your lifestyle and health. This quick phone call can last anywhere from 10-20 minutes, and to show our appreciation, CBCS will send you \$10.