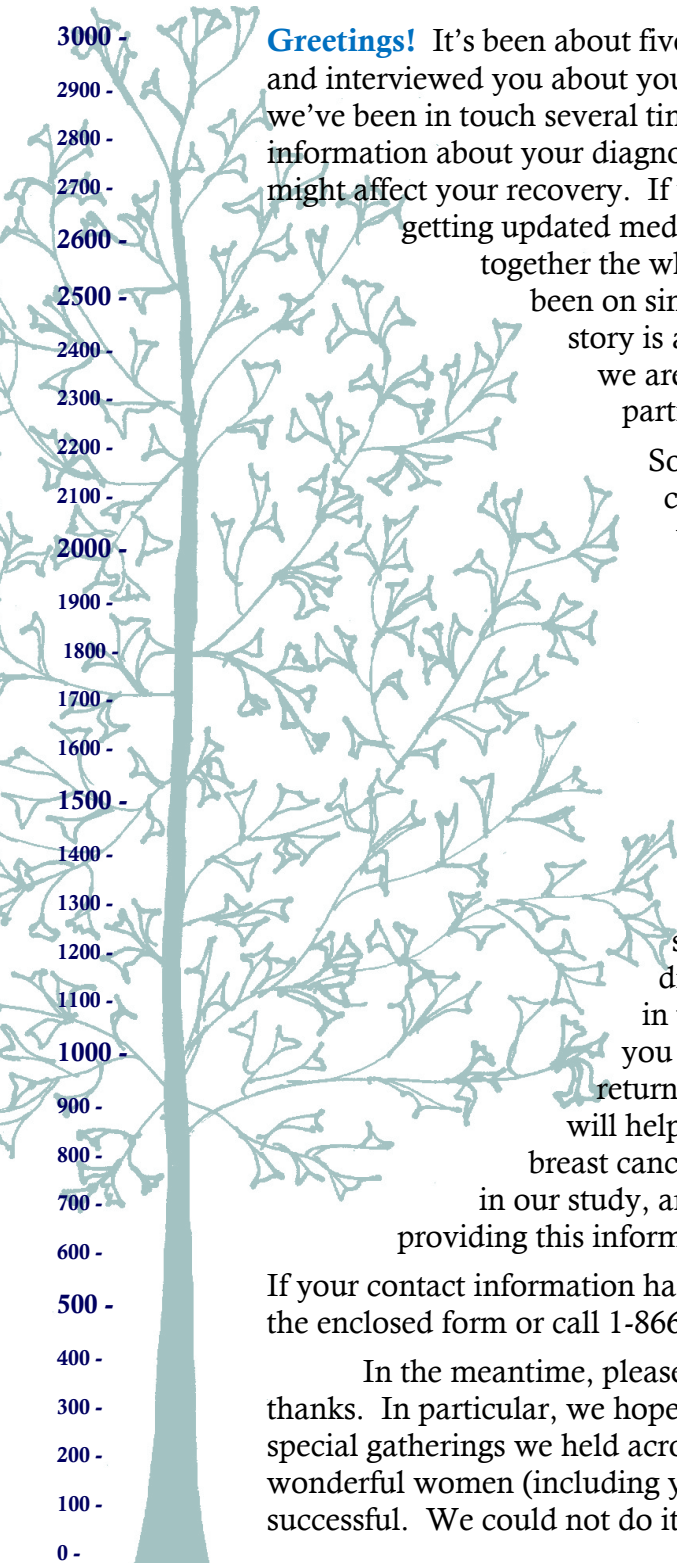


CBCS Newsletter

For Study Participants

Phase III: The Jeanne Hopkins Lucas Study



Greetings! It's been about five years since we came to your home and interviewed you about your life before breast cancer. Since then, we've been in touch several times by telephone and mail to collect information about your diagnosis, treatments, and life events that might affect your recovery. If you gave your permission, we've been getting updated medical records so that we can piece together the whole story, the journey that you've been on since your breast cancer diagnosis. Your story is an important part of this research, and we are so thankful to you for your continued participation.

Soon, one of our interviewers will be calling on you once again to share with us what's been happening with your health since the last time we talked.

We want to know how you are doing at this point, so that we can better understand this disease and the way it affects women from all walks of life. We'll also ask if you would be willing to fill out a survey by mail about quality of life, physical activity, treatment decisions and other issues that women may face several years after a breast cancer diagnosis. You can complete the survey in the privacy of your own home, and you will receive a \$25 check when you return the completed survey. Your answers will help us to understand the impact that breast cancer has had on the lives of the women in our study, and we hope you will consider providing this information.

If your contact information has changed, please update and return the enclosed form or call 1-866-927-6920 with your new information.

In the meantime, please accept this latest newsletter with our thanks. In particular, we hope you will enjoy reading about the special gatherings we held across the state in honor of the brave and wonderful women (including you!) who have made this study so successful. We could not do it without your help.

*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, Susan G. Komen, and the National Cancer Institute*

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

Follow-Up Issue #6

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VISIT OUR NEW WEBSITE!
<http://cbcs.web.unc.edu>

Recruitment Complete! Together, we did it! **3,000 women** are now enrolled in CBCS. Our ginkgo sapling has grown into a beautiful, full-grown ginkgo tree, thanks to your participation!

Surviving Breast Cancer — What Happens Next?

Somewhere in the middle of breast cancer treatment, a woman might begin to ask herself: Is there life after breast cancer? What does that life look like? In fact, about 2.6 million women in the United States who have been treated for breast cancer are learning the answers to these questions every day.

The Five-Year Mark

Today nearly nine out of ten women with breast cancer live more than five years after their breast cancer diagnosis. Research published in the *Journal of the National Cancer Institute* in August 2008 found that 89 percent of women who survive for five years will survive for the decade, and 81 percent will see 15 years. Thirty years ago, only half of breast cancer patients could expect that outcome. Medical technology, research and the dedicated efforts of breast cancer survivors continue to make it possible for women to live long, high-quality lives after diagnosis and treatment.

For many women, the risk of a recurrence is slim. Nonetheless, a woman who has just successfully beaten her cancer through months of grueling treatment and surgery might be surprised by this fact and the new goal: Surviving for five years.

Breast cancer survivors must continue to visit their doctors regularly and participate in regular screenings for cancer. Women who are going to be taking medication to help prevent a recurrence should ask about its side effects and monitor their body's reaction to the drugs. In addition, they should be aware of the following factors that can affect their quality of life after cancer:

Post-treatment aches and pains: Breast cancer survivors might notice new aches and pains in their joints and the muscles and tissues of the arm and chest where they received treatment. Women should let their doctors know about changes in their comfort and physical abilities. Physical therapy and lifestyle changes, such as getting more sleep or adopting a new exercise program, can help ease some symptoms.

Staying active and involved: Breast cancer survivors are a crucial source of information and support for newly diagnosed women. Getting involved with support groups and fundraisers is a valuable way in which breast cancer survivors can further research and awareness, as well as offer other women a sense of community.

Sexuality: Breast cancer survivors face a number of challenges as they learn how to be sensual and comfortable in their bodies after treatment. Women who have had surgery have to adjust to the new shape and feel of their body. Chemotherapy can alter a woman's sex drive and cause vaginal dryness. Although many women are reluctant to discuss sexuality with their doctors — and many doctors are reluctant to ask — it is important to talk to a primary care provider, therapist or gynecologist about any problems, such as reduced interest or pleasure in sex, that arise after treatment.

Lymphedema: Women whose treatment included surgery or radiation of the lymph nodes are more likely than others to develop a buildup of fluid in

the arm closest to the surgery, called lymphedema. Breast cancer survivors should know the signs of lymphedema and contact their doctor if they notice swelling or water retention in the arm. Gentle stretching, physical activity, yoga and pilates may be recommended to help prevent lymphedema.

FOR MORE INFORMATION: The National Cancer Institute offers a list of organizations that provide support and information to breast cancer survivors. Go to www.cancer.gov and type "national organizations" in the search field.

Infection: In women who have undergone removal of lymph nodes, there is an increased risk of infection in the affected area. Infection risk is also increased in women with lymphedema. Being alert to signs and symptoms of infection is important. These signs and symptoms include warmth, redness, pain and fever. Prompt treatment of an infection can hasten resolution and help avoid further complications.

SOURCES: "Risk of Relapse Low After Surviving Five Years," Aug. 13, 2008, *USA TODAY*; National Cancer Institute (www.nci.nih.gov); American Cancer Society (www.cancer.org) Written by Madeline Roberts Vann, MPH Reviewed by Susan L. Luedke, MD St. Louis Cancer & Breast Institute St. Louis University Medical Center Last updated September 2008.

SURVIVOR *Diaries*

Support Makes the Difference

I'm a one-year breast cancer survivor. I am very lucky, I have a wonderful support group with my husband and five children. I also have a great medical support group that carried me through this detour in my life. I just wanted to thank you and your team for the research and study you are doing. I know it will save lives. Please tell everyone you work with the tremendous work they are doing is a blessing in the lives of women they have touched and the women that they will touch in the future. May God bless you all in all that you do for others and may He support you in your personal lives that allows you to do this very important work. Thanks is just not enough, I just don't know how else to express my appreciation.

- Submitted by M.C., Wake County, NC

CBCS Hosts Special Gatherings To Thank Study Participants

The Carolina Breast Cancer Study hosted several reception events in the Fall of 2013 for women enrolled in the study and their guests. The purpose of the events, sponsored by UNC's Lineberger Comprehensive Cancer Center, was to honor and thank our participants and their caregivers. Because the women in our study are from counties all across North Carolina, the events were held in



Cat Andrews, Presenter
CBCS Telephone Interviewer

Topics included: breast cancer advocacy; study highlights from 1992 to present; the science of breast cancer; an "Ask the Expert" Q&A session; and an interactive discussion about better self-care and stress management. Perhaps most memorable was an uplifting and humorous presentation choreographed by Cat Andrews



Sara Williams, Presenter
CBCS Telephone Interviewer

four cities -
Wilmington, Concord, Greenville, and Chapel Hill.

The half-day reception event also included presentations prepared especially for our participants' benefit and enjoyment. Presenters included graduate students and staff, local health care providers, as well as representatives from UNC-Chapel Hill and UNC Hospitals. Local medical professionals and resource providers also attended as exhibitors.

on the "ups" and "downs" of surviving breast cancer, and a passionate call to advocacy delivered by Sara Williams. Both women are CBCS staff (telephone interviewers) and long-time breast cancer survivors.

Feedback provided from the women who attended the events has been extremely positive, and we look forward (hopefully!) to conducting similar events in the future.



Valarie Worthy, Presenter
Sisters Network Triangle
NC

Stories of CBCS Participants Memorialized in "Living Tree" Display

As part of the special gatherings we held in the Fall of 2013, we invited participants to share their breast cancer journey or experiences in the form of a story, poem, picture, or token to be displayed at the events. Thus, the "CBCS Gingko Living Tree" was born. The display was designed and constructed by CBCS staff, and the "leaves" are a presentation of the many inspirational messages of strength, hope, and faith that we received. Here are some of the beautiful entries that are now a permanent part of this living testament to the brave women in our study (more leaves/stories can be found on our website at cbc.web.unc.edu). Enjoy!

The CBCS Gingko Living Tree Display



I am so grateful for:
One more sunrise
Caring friends
Thorough doctors and nurses
My hair and eyelashes
God's mercy

Story:

When I received the report that I was diagnosed with breast cancer, at first, I was shocked as well as devastated. After the initial shock, the next day I told myself, "I can get busy dying or get busy living." I chose to "get busy living!" today, I am 2 years in remission and looking forward to the rest of my life of being cancer free.
Quote: Choose 2 Live!!!



Cancer is a bully
We must fight back
It may rob you
Of your life
If you do not stand up ☺



Family is everything!

I was blessed to have my faith in God, my family, friends and co-workers from Sampson and Duplin County Schools to go through my experience of breast cancer. My husband and my children helped to face cancer with endurance and strength.

Every day is a birthday when dealing with cancer. You learn to really appreciate life.

Keep on going no matter what life throws at you!
In other words don't give up!!

To all travelers on this journey:
Know this road is a challenge to all who travel along it.
Know that it looks different to each of us.
Know there are deep valleys, high mountains and many level plains.
Know there are people to assist you.
Know there are blessings in many odd forms.
Know you will travel the spiritual and emotional road as well as the physical one.
Find your guide in your faith.
Stop, look, enjoy moments of hope and glimpses of beauty.
Allow yourself to be hugged and give hugs when you can.
Life indeed is a journey and this part of it, the cancer part, is only part of it.

Peace,

