

CBCS Newsletter

For Study Participants

Phase III: The Jeanne Hopkins Lucas Study

Hello again! We hope this edition of the CBCS newsletter finds you well. You have been participating in the Carolina Breast Cancer Study for almost eight years, and the information you have provided is being used by many researchers who want to learn more about the diagnosis, treatment and outcomes experienced by women with breast cancer. We are now also researching risk factors for recurrences and second breast cancers. At their next telephone call, women who have had a recurrence or another breast cancer will be asked for their consent to obtain additional tumor samples for comparison with samples from their initial diagnosis. This information will help us to better understand why some

breast cancer tumors return and how to stop the spread of breast cancer.

We won't be contacting you by phone at this time. Our next follow-up call is scheduled for about a year from now. In the meantime, please accept this newsletter with our thanks. The "Survivor Diaries" section includes words of strength and hope from our participants. We have also included an article for breast cancer survivors who have experienced a recurrence, as well as some published research findings. Visit our website for other research findings and study information (cbcs.web.unc.edu).

If your contact information has changed, please send us an update using the enclosed form and pre-paid envelope, or call us at 1-866-927-6920. Thanks once again for making this study the best it can be! We know your time is valuable, and we appreciate your participation. We couldn't do it without you!

YOUR PARTICIPATION MATTERS! We have enrolled 3,000 women in this study. Of those, 95% completed 9-month follow up calls, 92% completed 18-month follow up calls, and 82% completed 38-month follow up calls!

We are conducting annual follow up calls with all who agree to further contact, so that we can obtain your updated health information. We look forward to speaking with you at your next scheduled call in about a year. From all of us at CBCS, **thank you** for your continued participation!

The ginkgo leaf is the symbol of the Carolina Breast Cancer Study. It was selected not only for its beautiful, graceful shape, but also because it is from a tree that will do well even under difficult conditions.



This balance of beauty, grace, strength, and persistence is a fitting symbol for the women in our 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, the National Cancer Institute, and Susan G. Komen

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

Follow-Up Issue #8

INSIDE THIS ISSUE:

If Breast Cancer Returns	2
Survivor Diaries	3
Research Findings	4

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susan g. komen.



If Breast Cancer Returns...

Many say facing cancer the first time was one of the hardest things they have ever had to do. There were many new things to learn and many tests to go through. When breast cancer returns (called a recurrence), you might know what to expect but that does not mean it is easy. Those who have a breast cancer recurrence often feel angry and afraid. It does not seem fair that the cancer they fought so hard to get rid of would come back. Some even second-guess the treatment choices they made. You made the decisions that were right for



you at the time. There is likely nothing more you could have done. Women may also wonder if they have the strength to go through it all again. If you have had these thoughts, you are not alone. It may be helpful to find a support group for women who have had a breast cancer recurrence. Never give up hope. You and your doctor will make a plan to treat your cancer. While it may be hard at first, continue to live your life as you wish. Try to find the energy to do the things that make you happy. Talk to others about how they can help you live well each day.

Types of breast cancer recurrence

A **local recurrence** is the return of cancer to the breast, chest wall or lymph nodes. Breast cancer can also spread to other parts of the body (called **metastasis** or distant recurrence). The risk of either type of recurrence varies from person to person and depends on the original breast cancer diagnosis and treatment.

A **second primary tumor** is a new breast cancer and not considered a recurrence. It develops in a different location from the original breast cancer (for example, in the opposite breast) and may differ in its characteristics.

A new treatment plan

Learn as much as you can. Find out as much as you can about the recurrence. The location and characteristics of the tumor may be different from your original breast cancer. Learning about your cancer will help you consider your treatment options.

Pick your medical team. You may want to use the same medical team you had before. You may want to ask different doctors to join your team. Even if your medical team is the same as before, get a second opinion. Other doctors may see things another way and can provide you with different information.

Choose your treatment goal. The location and extent of the recurrence will affect your treatment goals. If you have a local recurrence, your treatment will aim to get rid of the cancer with some combination of surgery, radiation therapy (if it was not part of initial treatment), chemotherapy, targeted therapy and hormone therapy. If metastasis is present, tests are done to see which organs are involved and to learn about the characteristics of the tumor. Talk to your doctor about treatment goals and options.

Don't face this alone. These are difficult choices to make. A patient advocate or co-survivor (family member or friend) can support you and help you weigh your options. Ask them to help take notes at doctor appointments, gather medical records and make sure you understand your treatment options. You do not have to face this alone.

Breast Cancer Resources

Susan G. Komen®
1-877 GO KOMEN
www.komen.org
American Cancer Society
1-800-ACS-2345
www.cancer.org
National Cancer Institute
1-800-4-CANCER
www.cancer.gov

How is a recurrence or metastasis found?

- * **Local recurrence** is usually found during a mammogram or a physical exam, either by a health care provider or yourself.
- * **Metastasis (or distant recurrence)** is usually found when symptoms are noticed and reported during follow-up office visits.

(This article can be found in its entirety on-line at: http://ww5.komen.org/uploadedFiles/_Komen/Content/About_Breast_Cancer/Tools_and_Resources/Fact_Sheets_and_Breast_Self_Awareness_Cards/If%20Breast%20Cancer%20Returns.pdf)

SURVIVOR *Diaries*



Submitted by N.C., Lenoir County: I have actively participated in the breast cancer study in hopes that it would help someone else. I have written a poem that entails a small part of my journey. Please share it with others if possible. Thank you.

Peace Within My Storm

The journey began at a challenging time,
My world spinning as a thin dime.
I, of course feared the unknown;
Unfailing faith kept me pressing on.
C - an ordinary letter of the alphabet;
The beginning of a word with much regret.
Regret for what I may never get to do
Hope to hold on to what? I had no clue.
Family played an essential part;
Helping me to keep joy within my heart.
Trials and test were all around.
Prayers that a positive result would abound.
The road to recovery, a difficult task;
Unanswered questions afraid to ask.
Several watchful eyes filled with tears;
Waiting to hear words to calm their fears.
When at last with unconditional love;
We received an answer from him above.
All is well, do not shake;
Joy cometh in the morning when you wake!!
I gained appreciation for each new day;
It seemed I had more and more to say.
Mother Nature's sky had even more blue;
Awakening me to brighter days anew.
As I approached the anticipated five year mark;
I anxiously pulled out everything left in the dark.
Again I was able to sail the Caribbean Sea;
Forever giving thanks for little ole me!!

Thank you to all our contributors to the CBCS *Survivor Diaries* section. You can find more stories on our website (cbc.web.unc.edu). If you would like to share your story, mail to address on front page, or email: cbc@unc.edu

THANK YOU!

Boxing Prayer

- Submitted by R.I., Guilford County

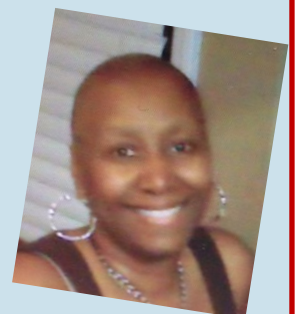
I said a prayer for you today.
That all your pain would go away.
I know it's hard to find courage every day
but I'll say a prayer that the cancer goes
away.
Don't give up and don't give in,
Don't let Cancer ever win.
Don't lose Faith and don't lose Hope.
Give that cancer the Rope-a-dope.

A Living Testimony

Submitted by M.C., Wake County

I thank God every day for my healing. I knew that the battle was not mine, but his. In the midst of chemotherapy and radiation I never questioned, I just knew I had to go through to get through. God had everything under control.

I say to the young, middle age, and the old: It is extremely important to do your self breast-exams (monthly) and to get a mammogram at least once a year. I am bringing awareness of this disease and asking all to get educated and know early detection so there will be a higher long-term survival rate. Take the time to ask about family history! Because there is no cure at this time, AWARENESS is the only way.



Carolina Breast Cancer Study Research Question:

Do women with the same type of breast cancer who receive the same treatment have the same outcomes?

This study is exploring the causes and outcomes of breast cancer in African American and white women.

RECENT STUDY FINDINGS

Alcohol Intake and Breast Cancer Risk

This study found that regardless of age, both African American women and White women who drank more than seven alcoholic beverages (beer, wine, liquor) per week had a higher risk of breast cancer than “light” drinkers (less than two drinks per week), although the risk was not as strong among white women.



We also found that African American women who had more than seven drinks per week were more likely to be diagnosed with the more aggressive subtypes of breast cancer than White women or African American women who were light drinkers.

Take-Home Message: Having one or more alcoholic beverages per day may be a risk factor for breast cancer. For African American women, the risk of getting a more aggressive subtype of breast cancer may be higher with increased alcohol use.

Smoking and Breast Cancer Risk

We already know from previous studies that smoking is a risk factor for heart disease, lung cancer, colon cancer and pancreatic cancer. This study looked at smoking and breast cancer risk, and we found that regardless of age or race, women who smoked for 20 years or more had an increased risk of breast cancer, compared to women who never smoked.

Take-Home Message: Long-term cigarette use may be a risk factor for breast cancer.



Quality of Life and Breast Cancer

This study looked at differences in physical and functional health-related quality of life scores between African American and White women in CBCS-III, measuring concerns such as fatigue, nausea, pain, returning to work, sleeping, and ability to enjoy things in normal life. We found that during treatment (surgery, chemotherapy, radiation), White women reported better health-related quality of life than African American women. After treatment, the gap narrowed, with African American women having only slightly lower scores in these areas than White women.



The study also compared differences in spiritual well-being and found that both during and after treatment, African American women reported better spiritual well-being than White women.

Take-Home Message: Improved socio-economic factors such as increased access to care and education may be associated with better health-related quality of life for breast cancer survivors.

Please visit our website (cbcs.web.unc.edu) to find links to all CBCS publications.

THANK YOU FROM ALL OF US AT THE CAROLINA BREAST CANCER STUDY!