

# CBCS Newsletter

## For Study Participants

Phase III: The Jeanne Hopkins Lucas Study

**G**reetings from CBCS! We hope you enjoy this edition of the CBCS newsletter. Thank you for sticking with us! You have participated in the Carolina Breast Cancer Study for almost nine years, and all the information you provided is being analyzed by researchers who want to learn more about the diagnosis, treatment, and outcomes experienced by women like you. Your continued participation will help us to better understand why some women get breast cancer while others don't, and how to stop the spread of breast cancer.

### Why the ginkgo leaf?

Many people have asked why the ginkgo leaf was chosen as the symbol of the Carolina Breast Cancer Study. The ginkgo tree is one of the oldest trees in the world and, because of this, is often referred to as a 'living fossil.' Recognized for its longevity, the ginkgo tree and its leaves are also well known for surviving times of adversity. Despite adversity, the ginkgo tree and leaves have persevered and are currently recognized as a symbol of hope, beauty, grace, and enduring strength. The women contributing their time and personal stories to the Carolina Breast Cancer Study all share the qualities of this amazing and beautiful leaf.

We will be contacting you by telephone within the next week or so to conduct a short telephone survey, and we'll send you a check for \$10 when you complete the phone call. If your contact info has changed, please send us your updates using the enclosed form, or call us at 1-866-927-6920 with your updated information. In the meantime, we hope you will enjoy our latest newsletter.

Inside you will find an article about issues faced by young mothers with breast cancer. The "Survivor Diaries" section includes messages of hope written by participants. We have also included some recent study findings and a "CBCS Spotlight" section highlighting one of our staff members.

As always, thank you for your continued participation in our study. We know your time is valuable, and we appreciate your help with this important research study.

**With your help, we've accomplished so much!** We have enrolled and are following 3,000 women! We hope to continue to collect data through 15 years of annual follow up calls with everyone. Study researchers are already conducting analysis, and several articles have been published using study data. For a list of publications and other items of interest, visit us at [unclineberger.org/cbcs](http://unclineberger.org/cbcs). From all of us, **thank you once again** for your continued participation! We couldn't do it without you!

*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 #9

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### Study Contact Information

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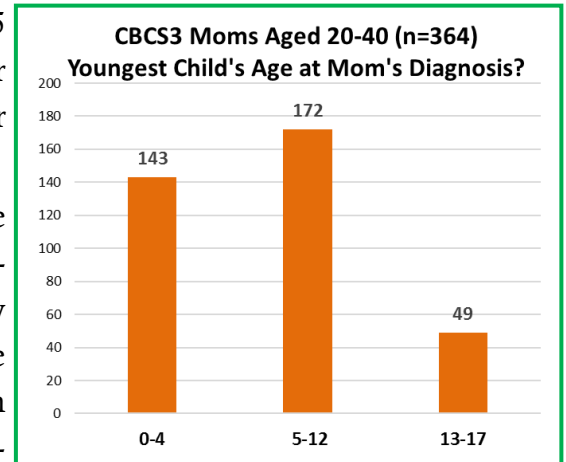
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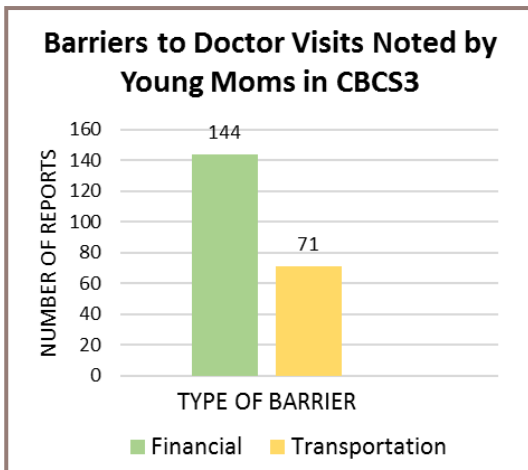
 **UNC**  
LINEBERGER

## When Young Mothers Are Diagnosed With Breast Cancer

CBCS3 enrolled 364 young women with children who were between 20 and 40 years of age at the time of their diagnosis. Of those, 84 had one child; 156 had two children; 83 had three children; and 41 women had four or more children at the time they were diagnosed. Further review revealed that for 39% of the young moms in our study, their youngest child was under 5 years of age at the time of diagnosis. For 47% of young moms, their youngest child was between 5 and 12 years old, and for 13%, their youngest child was between 13 and 17 years of age.



The data collected in this research study does not include specific research questions to address some of the obstacles experienced by young mothers with breast cancer. However, we do know that younger African American women are diagnosed with more aggressive subtypes of breast cancer more often than older women or white women. We also have data about marital status at diagnosis, income status, and insurance status. This data can be analyzed to determine how these factors may influence the unique challenges women with children face when they receive a cancer diagnosis.



## Resource Navigation Unit

During our telephone contacts with participants, we discovered that many women were struggling with meeting the new demands a diagnosis of this type requires, and they did not know where to turn. Of 364 women who were 40 years of age or younger, 31% (144) indicated during one or more of our annual telephone calls that there was a time when they wanted to go to a doctor but could not, because of financial issues, and 15% (71) indicated a time when they wanted to go to a doctor but could not, due to transportation issues.

In response, CBCS staff formed a resource navigation unit to identify and share publicly available resources and information with study participants. When speaking with women who share with us that they lack or need some type of assistance, staff members help participants to identify resources that address barriers to obtaining treatment or care, including financial pressures, transportation needs, social support, and insurance issues. This unit has linked many participants with resources across North Carolina. Of note, we have assisted over 100 women under 45 years of age, many of them young mothers at the time of diagnosis. The issues encountered have included financial, insurance, transportation, and childcare. We maintain an informal list of statewide resources by county that may be able to provide assistance. If you would like more information, please call us and speak with one of our telephone interviewers, who can provide you with links to a number of available resources for women dealing with breast cancer.

### Breast Cancer Resources

Susan G. Komen®  
 1-877 GO KOMEN  
[www.komen.org](http://www.komen.org)  
 American Cancer Society  
 1-800-ACS-2345  
[www.cancer.org](http://www.cancer.org)  
 National Cancer Institute  
 1-800-4-CANCER  
[www.cancer.gov](http://www.cancer.gov)

# SURVIVOR *Diaries*

## The Cancer Game

Cancer is scary, cancer is strange,  
 Sometimes it's hard to put a face  
 to the cancer game.  
 It affects the young, babies, and the old.  
 Sometimes that cancer is just plain cold.  
 Cancer has no rhyme or reason, it's a natural fact.  
 But because of cancer I'm gonna take my life back.  
 I'm gonna get in shape, eat right and take my pills.  
 I hope and pray I'll never be ill.

*Submitted by R.I, Guilford County*

## My Walk with Cancer

I contributed to the cancer walks long before I was ever diagnosed. I did so in memory of two aunts, one the sister of my mother, the other a sister of my father; both of whom lost their battle. I contribute and walk now in support of myself, my daughter, my sisters and all women who are potential SURVIVORS!



Cancer has taught me to be grateful! Life is precious – I am a survivor! That is a lot to be thankful for. My participation in the Carolina Breast Cancer study was my effort to assure other women a brighter, healthier future. It will be so, because we will find a cure for cancer!

*Submitted by M.H., Mecklenberg County*

Thank you to all our contributors to the *Survivor Diaries* section. Find more stories at [cbsc.web.unc.edu](http://cbsc.web.unc.edu). If you would like to share your story, mail to the study address on cover page, or email to: [cbsc@unc.edu](mailto:cbsc@unc.edu).

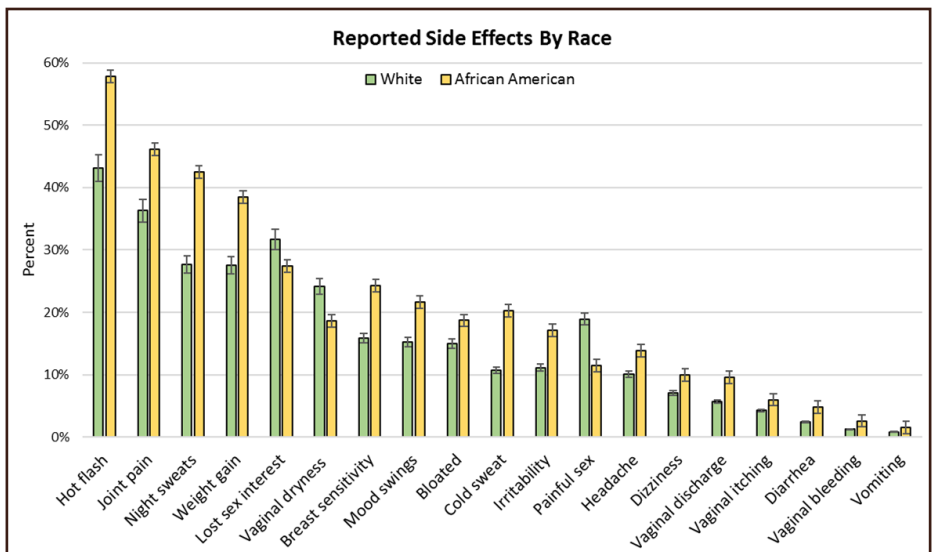
## Recent Study Findings

### Endocrine Therapy Adherence and Reported Side Effects

Endocrine therapy (such as Tamoxifen or Femara) is a vitally important part of treatment for women diagnosed with hormone receptor-positive (HR+) breast cancer, the majority of all breast cancer cases. Taken as prescribed, endocrine therapy can reduce the risk of recurrence and breast cancer-specific mortality in this group.

In our study, 24% of African American women and 16% of white women with HR+ breast cancer reported not taking their pills as prescribed (non-adherence). Younger and pre-menopausal women were more often non-adherent, as were those women insured by Medicaid and those making less than \$15,000 per year. Some reasons for non-adherence included having trouble remembering to take the pills, cost of pills, and side effects. African American women more often reported that they believed their risk of breast cancer recurrence was very low (56% versus 34% of white women), despite the fact that African American women in the sample had more advanced stage than white women, on average. African American women were also more likely to say that they believed their risk of breast cancer recurrence would not change if they stopped taking ET (21% versus 9%).

**TAKE-HOME MESSAGE:** Effective culturally tailored communication between patients and providers discussing side effect risks, benefits in terms of reduced recurrence risk, and behavioral skills such as self-management coping strategies is needed to reduce non-adherence and to improve breast cancer outcomes for all.





# CBCS Spotlight

## Linda Shaw



**What Linda Does:** Linda conducts phone surveys with our study participants to obtain updated treatment, health, and lifestyle information.

**Linda’s Story:** At the age of 45, Linda was diagnosed with early stage breast cancer in 2008 and went through a year of surgery, chemotherapy and radiation. Linda is now a strong advocate for self breast exam, because her mammogram did not show breast cancer just a few months before. She was also surprised to learn she had no risk factors except for being one of the “1 in 8” women who gets breast cancer. After completing treatment, Linda went to work as a research nurse where she discussed end of life issues with dialysis patients. She found this work to be extremely rewarding and was surprised to find that she no longer thought about breast cancer every single day. After six years, Linda was excited to learn from her doctor that she would graduate to the Survivorship Program! To be safe, she requested a “goodbye MRI” before saying “goodbye” to her oncologist. But a new breast cancer was discovered, and treatment began all over again.

Recently, Linda talked with her two boys, who were in middle school when she was first diagnosed, about what they remember from this time in their lives. Here is a portion of what they shared: “I remember feeling afraid that I was going to lose my mother, though I had difficulty processing my fears in constructive ways. I would lie in bed, crying softly at the prospect of no longer having a mother. Eventually, I grew sick of the tears and I promised that I wouldn’t cry again unless you died. At the time I felt very grown up and strong, but now I realize that this response closed me off from processing feelings of pain and sadness in a healthy way. I was afraid to talk to you or Dad, because I didn’t want you to worry about me. Looking back, I think it could have helped fourteen-year-old me to go to a counselor or therapist, where I might have found a safe space to talk about how I felt. Cancer is really confusing and terrifying, and there can be guilt associated with feeling bad while your parent is going through a much greater deal of physical and emotional pain. Being able to talk through healthy ways of coping with these feelings would have helped me, and I think other children would benefit if counseling services were offered to them.” Linda has since talked with her own doctor about the need for providing counseling services for children and guidance for parents as an integral part of the process when mothers of young children are diagnosed.

Linda is thrilled to be part of the Carolina Breast Cancer Study team, which she joined in 2016. She finds it an honor to talk with other breast cancer survivors about their “journey.”

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