

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, the Komen Foundation, and the National Cancer Institute

“Beauty, grace, strength, and persistence...”

Follow-Up Issue #4

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Study Contact Information

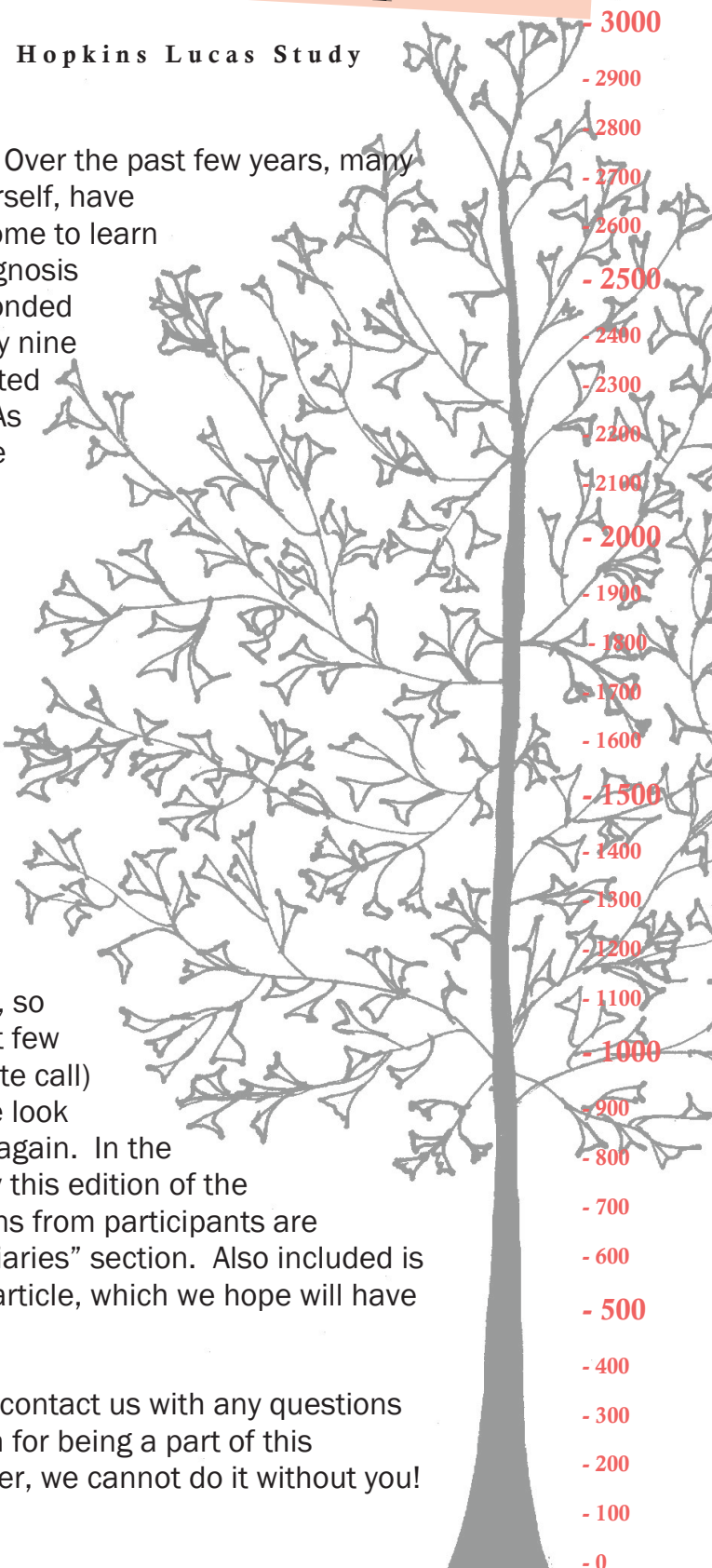
UNC-Chapel Hill
LCCC-North
1700 MLK Blvd, Rm 332
CB # 7294
Chapel Hill, NC 27599-7294

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

Thank you, **Survivors!** Over the past few years, many women, including yourself, have invited us into their home to learn about their breast cancer diagnosis and treatment. They’ve responded to mail or phone contact every nine months or so to provide updated medical record information. As breast cancer survivors, these remarkable women have shared important information with us that will hopefully help us to understand what types of breast cancer are occurring among different age groups and races, learn what types of treatments are being offered, and observe what outcomes those treatments are providing. We are very grateful for your participation in this effort.

It’s time for another follow-up, so we’ll be calling you in the next few weeks (a short 10 to 15 minute call) to see how you are doing. We look forward to speaking with you again. In the meantime, we hope you enjoy this edition of the CBCS Newsletter. Submissions from participants are showcased in the “Survivor Diaries” section. Also included is a breast cancer survivorship article, which we hope will have meaning for you.

As always, please feel free to contact us with any questions or concerns. Thank you again for being a part of this important research. Remember, we cannot do it without you!



Recruitment Complete! As of October 2013, **3000 women** are enrolled. Our ginkgo sapling has grown into a beautiful, full-grown ginkgo tree. Many thanks for your participation!



SURVIVORSHIP

According to the National Cancer Institute (NCI), more people are surviving cancer than ever before. The NCI estimates that there are now two million breast cancer survivors in the United States today. While survivorship is the goal of treatment, reaching and living it does not mean life becomes less complicated.

When do I become a breast cancer survivor?

The short answer, immediately. From the very instant you receive your diagnosis of breast cancer until you take the very last breath of life, you are a survivor. It doesn't matter if you are still in treatment, don't have all your hair back or at what point anyone else starts their count.

There may be times when you don't feel like a survivor—times when you wonder “why me?” or “why now?” You may never know the answers to those questions. In fact, some people respond to that way of thinking by asking, “why NOT me?” and “why NOT now?” Who ever heard of a good time to be diagnosed with breast cancer? Dealing with these questions and your feelings is part of the healing process. It doesn't happen in an instant, and sometimes it takes a long time to come to a place of acceptance. No matter how long the healing and acceptance takes, you are and will remain a survivor.

Which doctor do I call when I have questions about my health?

There are some people who do not have a “regular doctor.” You will need to decide which doctor will provide your cancer follow-up care and which one(s) will provide other medical care. For follow-up breast cancer care, this may be the same doctor who provided your cancer treatment. For other medical care, you can continue to see your family doctor or medical specialist as needed. If you don't have a family doctor, your oncologist may be

able to provide you with a referral, or ask people in your community for a recommendation.

Depending on where you live, it may make more sense to get cancer follow-up care from your family doctor than to travel long distances to see an oncologist. No matter who you choose as your doctor, try to find those with whom you feel comfortable. Make sure any doctors you see have updated copies of your medical records.

What's next for me?

There is much written about diagnosis and treatment of breast cancer. However, what happens to a cancer survivor goes far beyond that moment of relief when treatment is finally over. For some, the treatment is continuous, so even that milestone does not come. Life goes on.

Making the transition from being a patient on active treatment to long-term follow-up and survivorship can be difficult for some cancer survivors, especially if they are having trouble coping with the physical, emotional and financial challenges. As survivors, we may want life to return to what it was like before, “back to normal.”

The fact is that our lives have changed forever, and we need to discover a new “normal.” Many cancer survivors talk about how their experience with cancer has given them “new life,” a different set of priorities, the motivation to do something they've always wanted to do (travel, climb mountains, skydive, paint, spend time writing, enjoy family time). We encourage you to persevere. As best you can, try to find a way to turn the difficult experience into something that brings about a positive change.

What Cancer Cannot Do

It cannot cripple Love
 It cannot shatter Hope
 It cannot corrode Faith
 It cannot destroy Peace
 It cannot kill Friendship
 It cannot suppress Memories
 It cannot silence Courage
 It cannot invade the Soul
 It cannot steal Eternal Life
 It cannot conquer the Spirit.

-Author Unknown

Written by Jamie Konarski Davidson,
 two-time breast cancer survivor

Excerpted from the Breast Cancer Resource Directory, 4th ed.

SURVIVOR *Diaries*

Submitted by G.J., Edgecombe County, NC

I was diagnosed with breast cancer three years ago. I had breast cancer! I was very, very scared. I didn't know what to do. The doctor told me that I would have to have surgery. My husband and cousin were very supportive - they stood by me every step of the way. When the doctor did the surgery, I had to lose my right breast because she said the cancer was in that one, and I was in the first stage. I didn't have to take chemo or radiation.

After the surgery, I thanked the Lord for working through the doctor. I put my faith in God and I look to Him for strength. I just had my check-up with my doctor and she said that I was doing fine. I have been cancer-free for three years - I am a survivor.



G.J. with her husband

Body Talk

Submitted by W.C., Mecklenburg County, NC

One night this past weekend, I had finally gone to sleep after dealing with intermittent pain throughout the day when the nerves and muscles in my right arm awaken me screaming "We are hurting! We are tired of this position!"

Before I could readjust the pillows under my arm, the drain area awaken and sent a familiar burning sensation through my shoulder. Then the pain shooting through my breast nipple made me moan and wish I had taken some medication before trying to get some sleep.

I wanted to get back to sleep without taking any medication (*it's the fear of becoming addicted to it, I told myself*). "Alright, everyone," I said, "calm down. I want to get some sleep before the sun comes up."

Right Arm: Fix the pillow then.

Drain: Stop moving so much. You're pulling my stitch.

Back: I'm not used to you sleeping this way. Why can't you sleep on your side?

I adjust the pillows, turn slightly to my left side and take a few deep breaths. "Can we go back to sleep now?"

Just as I relaxed, I heard Arm, Shoulder and Drain arguing about who had awakened everyone else. They sounded like little children trying to determine who had broken the window.

"You woke us up."

"No, I didn't."

"Did too."

"Did not."

Me: "Will all of you be quiet?! Just go to sleep, please."

Arm and Shoulder: We're awake now.

And pains shot through the upper half of my right side.

I look at the clock. 4:00 a.m. Frustrated, I get up.

Body: What are you doing?

Me: We are going walking.

Body: It's cold and dark outside!

Me: And your point is?

Body: I don't want to go!

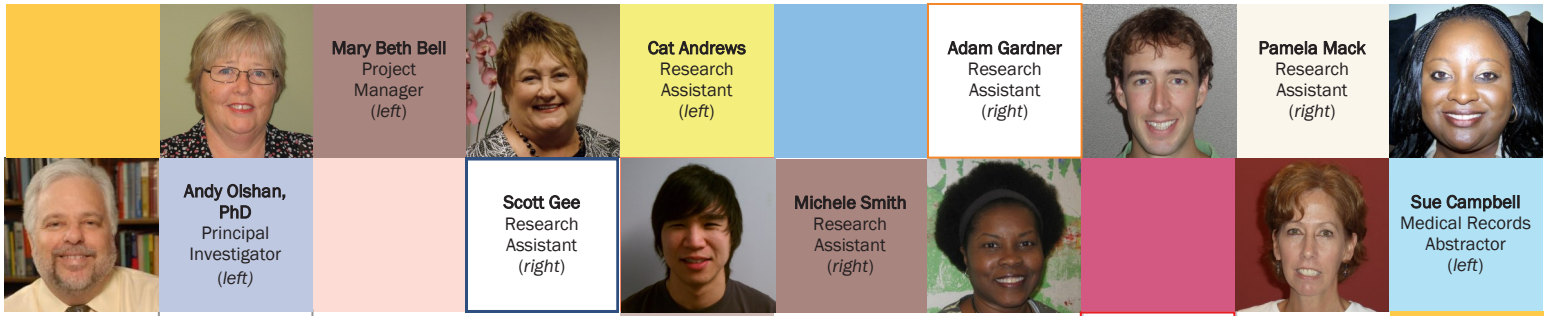
Me: Too bad.

I dressed slowly and headed for the front door. As I stepped outside, a cold rush of air entered my lungs and my Body shuddered and said, "I don't want to do this! It's too cold!"

Me: Then you should have gone back to sleep!

I slowly walked two blocks from my house. When I reached the turnaround point, I took several deep breaths and looked up at the gorgeous full moon. How beautiful! How bright! As I started back home, I realized the Body was quiet (there was less pain) and it was focused on getting one foot in front of the other.

I kept looking at the moon as it brightened my quiet neighborhood. Waves of peace and calm flowed from my head to my toes. At that moment, I knew that I was still in God's hands.



CBCS Spotlight

Sara Williams



What Sara Does: Sara has served as a telephone interviewer for the CBCS since 2008, and has no doubt talked to most of you already when you first agreed to participate. She loves being able to connect with all her “sisters” across the state and encourage them to be a part of this important research!

Sara’s Story: When Sara was diagnosed in 1997 at the age of 46, she knew absolutely nothing about breast cancer, although she had spent over a decade working in the international health field. Sara quickly became involved in breast cancer advocacy and support groups, as well as breast cancer research projects. She is a graduate of Project LEAD (“Leadership, Education, and Advocacy Development”), the National Breast Cancer Coalition’s innovative/intensive science program for breast cancer activists. She has also served as a peer reviewer for the California and Department of Defense Breast Cancer Research Programs, Susan G. Komen for the Cure, Avon Breast Health Outreach Program, American Cancer Society Stakeholder Program, and the Cochrane Collaboration’s Breast Cancer Group. Her passion for research led to full-time employment within the breast cancer arena, first in 2001 to develop recruitment strategies for the Sister Study, a national NIH-sponsored research study to discover the environmental and genetic causes of breast cancer, and now with CBCS.

Sara’s mother, Peggy Blum Hill, was always so proud to tell others of her daughter’s good work. Her mother even gave out Sara’s phone number to complete strangers because she knew her daughter would help them. In 2009, when Sara’s mother received her own breast cancer diagnosis at age 82, her family and friends were stunned. Sara could only think, “Breast cancer? Again? Mom’s diagnosis was more devastating than my own.” Because the breast cancer was already metastatic, they knew there was nothing they could do to save her. Only two months elapsed until her mother’s death. Sara is lifted up, however, every time she hears women on the other end of the phone say, “You had breast cancer how many years ago?” She loves it that breast cancer doesn’t bat a thousand!

Sara’s Message: “Like me, I hope you are honored to be part of the best and brightest research around as we strive to find better treatment and, hopefully, a cure for this disease that still takes away OUR best and brightest.”

Thank you for all your help with the Carolina Breast Cancer Study. We’ll be in touch soon. In the meantime, please contact us with any address or telephone changes:

Mail: Carolina Breast Cancer Study
 UNC-Chapel Hill, LCCC-North
 1700 MLK Blvd., Rm. 332
 Chapel Hill, NC 27599-7294

E-mail: cbbc@unc.edu

Phone: 919-966-9439 or 1-866-927-6920