



Greetings from all of us at the Carolina Breast Cancer Study!

The study is in full swing. Our goal is to enroll 3,000 participants. As you can see by our ginkgo tree, we're enrolling more and more women every day. After our in-home interview, we're following up with our study participants by telephone every nine months. These phone calls will help us understand the treatment choices and health outcomes of all the women in our study.

What to expect for your next follow-up phone call:

It has been at least 18 months since a nurse came to your home to interview you, and nine months since we last spoke with you on the telephone. We want to know how you are doing, so we'll be contacting you shortly for our second follow-up call. So far, we've been able to reach almost all of our participants at the first follow-up. We hope that you, too, will continue to take part in the follow-up interviews for our study.

This second phone call will be similar to the first in many ways. We'll ask about your doctor visits and treatments. Additionally, we'll request that you sign new medical records release forms so that we may obtain your latest medical records from your doctors.

We'll also ask you to complete a mail-in survey about your quality of life and any health issues you've been having. This short survey will take only about 10 minutes to complete in the privacy of your own home. For your convenience, we'll provide a postage-prepaid return envelope. You don't have to complete this survey to remain in the study, but we hope that you will. Your answers, in addition to the answers of the other women in the study, will allow us to piece together the whole story of breast cancer.

Remember that just like a jigsaw puzzle, the picture only becomes complete when every woman adds her piece, her life experiences, to the whole.

Thank you for everything you do for our study. By sharing your story, you are helping future generations in the fight against breast cancer.

Sincerely,

Mary Beth Bell

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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 #2

INSIDE THIS ISSUE:

Lymphedema: A Call to Arms	2
Survivor Diaries	3
The Resource Navigation Unit	3
CBCS Spotlight: Michele Smith	4

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Chapel Hill, NC 27599-7294

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Email: cbcs@unc.edu
<http://cbcs.med.unc.edu/>

Lymphedema: A Call to Arms

WHAT IS LYMPHEDEMA?

Lymphedema (pronounced LIMF-uh-DEE-muh) is a chronic and potentially disfiguring condition. The literal meaning is “swelling of the lymph” which can result from an accumulation of lymphatic fluid, often in the arm(s).

WHAT IS THE FUNCTION OF THE LYMPHATIC SYSTEM?

The blood carries nutrients to the cells for nourishment and the lymph system carries away any of the excess fluid and waste from these cells. If the lymph system is damaged and the waste is not carried away effectively, lymphedema can occur.

WHAT CAUSES LYMPHEDEMA?

Lymphedema can develop when lymph nodes are removed or when the surrounding tissue is damaged or scarred by radiation therapy for breast cancer. This can lead to a collection of lymphatic fluid in the affected area. Lymphedema may develop immediately, or it may occur several weeks, months or even years after breast cancer surgery or radiation. Lymphedema of the arm tends to develop gradually in 15 to 20 percent (or more) of breast cancer patients who have lymph nodes removed.

HOW IS LYMPHEDEMA DIAGNOSED?

Lymphedema can be diagnosed by a physician through a physical examination and by measuring the arm(s). Women with lymphedema may be referred to a trained lymphedema therapist.

WHAT ARE THE SIGNS AND SYMPTOMS OF LYMPHEDEMA?

Symptoms include fullness or tightness in the arm, pain and/or aches, swelling or redness in the arm, loss of flexibility in the arm, hand, or wrist. Sufferers may notice that rings and/or bracelets do not fit as easily, or one arm is actually somewhat larger or feels warmer than the other arm.

HOW CAN I PREVENT LYMPHEDEMA?

Particularly during spring and summer, breast cancer patients should take care when gardening or engaging in outdoor activities. Avoid **insect bites, cuts, falls**, or stress from **heavy lifting**, as these mishaps may trigger infection or worsen lymphedema. Avoid **needle sticks, blood tests, blood pressure testing, allergy tests** or **medical procedures** of any kind on the affected arm. Avoid **hot tubs** and **saunas**. Avoid **chemical underarm hair removers**, and use an **electric razor** to avoid cuts and nicks. While housecleaning, **wear gloves** to avoid **chemical exposure**. During air travel, always **wear a compression sleeve**.

HOW IS LYMPHEDEMA TREATED?

There are several ways to treat lymphedema. This includes physical therapy, compression bandaging/garment, or a specialized massage called Manual Lymphatic Drainage Massage. If lymphedema is caused by infection, antibiotics are often prescribed.

Special thanks to Cat Andrews and Sara Williams for compiling this information. Cat is an 20-year breast cancer survivor and works on Follow-Up for the CBCS. Sara is a 14-year breast cancer survivor and the Enrollment Specialist for the CBCS. Both women live with lymphedema.

FOR MORE INFO ON LYMPHEDEMA:

- The National Lymphedema Network:
www.lymphnet.org, or toll-free: 800-541-3259
- The Breast Cancer Resource Directory (4th Ed.) pages 43-44
- www.lymphedemapeople.com
- www.lymphnotes.com



This customized compression sleeve can prevent further swelling in an arm affected with lymphedema.

SURVIVOR *Diaries*

An excerpt from a letter submitted by V.M., Onslow County, NC:

I could write a book. I was diagnosed with inflammatory breast cancer. I have been through a lot: 3 courses of chemo and radiation for 15 days straight. I also have lymphedema because they took out 11 lymph nodes. They even stopped my Medicaid, so I had to move from my family before they gave it back to me. I've been holding on to God all I know how, and I know He is with me. I'm hoping that you will find a cure for cancer because I want to live. I'm 49 years old, with two beautiful grand-kids that I love and fight so hard to be with. I haven't taken any pictures since I've lost my hair, but the next time I write, I will send one.

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: cbcsc@unc.edu

Submitted by C.T., Johnston County, NC:

As a Health Educator for more than 30 years, I have spoken to women's health groups and trained what we still call "Lay Health Advisors," those community women out on the front lines reminding us to check our breasts. Yet, I was in disbelief when I was diagnosed with breast cancer! In my case there was no genetic link or family history, and I've always been health conscious regarding diet and exercise. So what triggered this? We still don't know. I was comforted by a doctor who told me that we all have these cells in our body, and that scientific research is being done to discover what causes our cells to begin that abnormal replication process.

To those of us dealing with cancer: Know that we are Victorious! Life should be lived each day as if there were no tomorrow. Just imagine how many people we could love in one day. Hope is good, but Faith is better than any medicine.



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.



CBCS Spotlight

Michele Smith



What Michele Does: Michele is one of CBCS’s social/clinical research assistants. She sends out thank-you letters to study participants, requests medical records, and enters the health information of our participants into the study’s database.

Michele’s Story: Michele has always been interested in health disparities and has been involved in various fields of research including hypertension, diabetes, and adolescent nutrition. Yet Michele’s true passion has always been in breast cancer research ever since her mother battled the disease.

In November 1982, Michele’s mother, Pat Stewart, discovered a lump in her breast and immediately called her physician. The tests revealed the worst: Pat had breast cancer. Initially, Michele’s family was told not to worry, as the cancer was discovered early. Surgery revealed, however, that the cancer was much more extensive than originally believed. To fight the cancer, Pat underwent long and aggressive treatments. Tragically, in November 1984, just two years after her diagnosis, Michele’s mother passed away at the age of 45.

“There have been many advancements in the treatment of breast cancer since the early 80’s and 90’s, when my mother was burdened with this disease. Every day I live with the fear of breast cancer and its devastation. Every lump, bump, knot, itch, or slight difference is always frightening. It is my hope that the Carolina Breast Cancer Study will yield some answers as to what causes this disease and possibly help point us in the direction of preventing it, not only for my sake, but for all women.”



Sara Williams
Research Assistant
(above)



Riza Bueser
Research Assistant
(above)



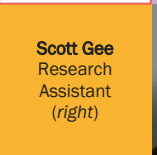
Roxan Brock
Nurse Interviewer
(above)



Judy Bryan
Research Assistant
(above)



Peter Samai
Graduate Research Assistant
(above)



Scott Gee
Research Assistant
(right)



Lisa Lacks
Nurse Interviewer
(right)



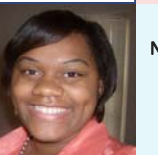
Adam Gardner
Research Assistant
(right)



Lela Family
Graduate Research Assistant
(right)



Dana Renn-Reep
Medical Records Abstractor
(above)



Nicole Caviness
Research Assistant
(left)