

CBCS Newsletter

For Study Participants

Phase III: The Jeanne Hopkins Lucas Study

Greetings! After almost seven years of interview data collection, the information you provided to the Carolina Breast Cancer Study is being compiled and analyzed to learn more about the breast cancer diagnosis, treatment and outcomes experienced by all our participants. Some recent study findings can be found on the back page of this newsletter.

As we have done each year since your in-home interview, we'll be contacting you by telephone within the next few weeks to update your health information. We'll be asking about your general health and any recent procedures or treatments you may have had. This information will help us to better understand the different types of treatments offered and how those treatments affect breast cancer outcomes. We'll send you a \$10 check to thank you for participating in this telephone interview.

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.

During this follow-up call, 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 answer the survey questions in the privacy of your own home, and you will receive a \$25 check to thank you for returning the completed survey. Your answers will help us to better 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.

We'll be calling you soon. Please let us know at that time if you want to participate in the mail-in survey. If so, we'll send you the survey and a business reply envelope for postage-free return mailing.

Until then, we hope you will enjoy the stories shared by participants in the *Survivor Diaries* section of this newsletter. Please let us know if you have updated

address and/or telephone information, as well as any questions about the study or your participation. Thank you, as always, for making this study the best it can be. We couldn't do it without you!

YOUR PARTICIPATION MATTERS! We have completed our baseline interviews with 3,000 women. Of those, 95% also completed the 9-month follow-up calls, and 92% completed the 18-month follow-up calls! We are still conducting annual follow-up calls with those who agree to further contacts so that we can obtain updated health information. **Thank you** for your participation!

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 #7

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SURVIVOR *Diaries*

My Bucket List for Survival and Healing

I want to thank you for your continuous commitment to cancer research and the ongoing fight against breast cancer. Although this dreadful disease affects many lives, we have come a long way in understanding and implementing treatments that save lives. I was diagnosed with Stage II breast cancer in 2009. My doctor immediately started the treatment process which included chemotherapy, radiation and finally surgery. I had both of my breasts and some lymph nodes removed. After shock, anger and ultimately thankfulness that it hadn't been worse, I was able to focus on survival and healing. Initially, I thought to myself, "Wow. This is terrible news." But after I completed all of the treatments, I took the time to reflect on everything that I had gone through. I then created a bucket list of things that I have always wanted to do. The first task on the list was to get closer to God and to strengthen my relationship with Him. The second task on my bucket list was to finish school (I dropped out of school when I was very young). The third and final task on my bucket list was to reach out to old friends in order to repair past hurts and restore relationships.

I have completed all of the tasks on the list! I meditated on healing scriptures, which kept me centered. I not only completed high school and obtained my GED, but I went on to college and will soon obtain my Associates of Science degree in Human Services Technology. Once I reached out to old friends and asked for forgiveness and also forgave them for past offenses, I was able to move forward in newness of life. I was able to live beyond the feelings of condemnation. I am healed and living the life that God planned for me to live. Having had cancer really changed my life for the better. It made me a better person, and I changed the way I thought about life and people.

-Submitted by SW, Mecklenburg County (edited to fit in available space)



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.

- Submitted by CL, Davie County

Breast cancer while pregnant – Some said it was too risky, both to me and my unborn child. Others said I was being selfish – I already had one child.
 I said it was fighting for my life as well as my unborn child.
 Was it fun – no. Was it easy – no.
 But it was necessary.
 Two years later I am 100% cancer free. I symbolize health, hope and happiness for those of us that were told it was impossible!

- Submitted by HF
 Mecklenburg County

I have been lucky enough to enjoy far more "ups" than "downs" in this life. Breast cancer was no different! It changed my life in ways that have had more of a positive impact than I ever would have experienced otherwise. Life takes interesting paths ... I am walking this one with many fortunate survivors and will continue to walk it with integrity and honor for all those less fortunate. Here's to them!!

- Anonymous

"If you can't fly, crawl."
- American proverb

Parts of the journey seem to never end and I had convinced myself I would never feel "normal" again. After months, and years, of crawling, I could start to see some wings.

Now I fly most of the time.

- Submitted by VF
Guilford County

A Poem of Courage

- Submitted by RI, Guilford County

Chemo took away my hair, my eyebrows, and my brain.
I thought I'd never be the same.
But by the Grace of God to carry me through
The next thing I knew, I had fibroids, too.
My stomach hurt, and I prayed and prayed
And I got bigger and bigger each day.
The next thing I knew, I couldn't pee or poop,
I went straight to the hospital to the surgery room.
I developed flesh eating necrosis, so back to the hospital again.
I thought to myself, when will this nightmare ever end.
I stayed about a month or two,
Until my insurance told me you have to shoo.
I went to Kindred Hospital, here I go again
I thought to myself, I really can't win.
I stayed there two months until I got stronger and stronger each day.
By the Grace of God, I finally went home one day.
I tell you my story so you can be strong, too.
Just remember God loves you.



Being told you have cancer changes you – it just does.
No matter how you choose to manage that news, it changes you.
Thankfully, the worst parts about those changes are over for me – I survived!
I choose not to allow that news to define me anymore than a brief moment in my life,
while I dealt with it, and live each moment to its fullest.
I'll never forget it, and I'll never let it have any more of my life!

- Submitted by SR, Mecklenburg County

...what an adventure this has been! I like to consider myself a "survivor in training." And I say that because every day is a new beginning. Every day I wake up is a good day! I can deal with the pain, the scars, both emotional and physical, because I am still here! I have been lucky. I have the love, strength and support of my wonderful family and some of the best friends EVER. I couldn't have done it without them. I try to do different things now, new things, because I am a different person, a new person. I hope I am, and always will be, a better person for having taken this journey.

- Submitted by JG, Guilford County

Thank you to all our contributors to the CBCS *Survivor Diaries* section, whose stories are reprinted here. We have also included some stories from the CBCS Living Tree, and more can be found on our website (cbs.web.unc.edu).

If you would like to share your story...

Mail to: Carolina Breast Cancer Study
UNC-Chapel Hill, LCCC-North
1700 MLK Blvd., Rm 332
CB # 7294
Chapel Hill, NC 27599-7294
or email: cbs@unc.edu

Carolina Breast Cancer Study Questions:

What risk factors influence the type of breast cancer a woman will get?

Why do younger African American women tend to get more aggressive forms of breast cancer?

How do racial disparities and access to care impact survival and quality of life for breast cancer survivors?

In other words...

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

The information we collect will help us address health disparities and find ways to prevent and more effectively treat breast cancer in the future.



Andy Olshan

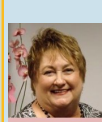


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Melissa Troester

Andrew F. Olshan PhD Principal Investigator
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Melissa Troester PhD Principal Investigator



Cat Andrews



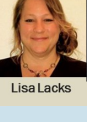
Sara Williams



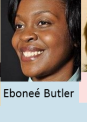
Nicole Gaviness



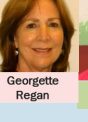
Roxanne Andrews



Lisa Lacks



Eboneé Butler



Georgette Regan



Lena Ehret



Sue Campbell



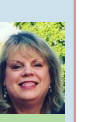
Marc Emerson



Sasha McGee

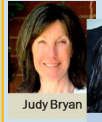


Jack Murphy



Linda Shaw

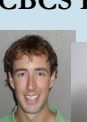
CBCS III TEAM - CURRENT AND FORMER MEMBERS



Judy Bryan



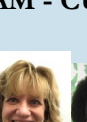
Pamela Mack



Adam Gardner



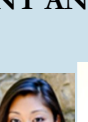
Scott Gee



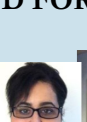
Erin Lutz



Michele Smith



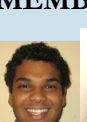
Riza Bueser



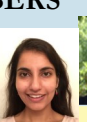
Leila Family



Nicholas Taylor



Peter Samai



Sarah Vohra



Celeste Cummings



Mary Beth Bell

Since 2008, our research staff of investigators, enrollment specialists, interviewers, research assistants and graduate students have enrolled and are following 3,000 women with breast cancer in North Carolina. Several staff are breast cancer survivors themselves, and others have been affected by the loss of loved ones due to breast cancer. This devoted research team hopes that our work on this study will have an impact on breast cancer research and on the women who are affected by this disease.

Robert Millikan, the study's Principal Investigator from 1993 until his death in 2012, devoted his career to breast cancer research, particularly with regard to racial disparities in screening, diagnosis, and treatment. We are dedicated to continuing his legacy in finding ways to improve breast cancer outcomes, and hopefully one day to help find a cure.

Thank you to all who have contributed to this important research – thank you to all of our supporters and to our participants. This study would not be possible without you.



Bob Millikan

RECENT STUDY FINDINGS

- * Breast density matters! We found that women with **extremely dense breasts** were three times as likely to get breast cancer than women without dense breasts. **Message:** *Regular mammography screenings are an important part of breast health care. In North Carolina, breast density measures are now included with mammogram results.*
- * An extended time lapse (30 days or more) between a breast cancer diagnosis and first medical consultation/starting treatment is called a **treatment delay**. We found that women who had a small household size (1 to 2 people), lost a job, or opted for immediate breast reconstruction experienced treatment delays more often than women who did not. For African American women, treatment delays were also associated with younger age at diagnosis and the type of treatment received. **Message:** *It is important to work with each woman individually to address her particular needs in order to ensure timely treatments for breast cancer.*
- * The American Cancer Society recommends that adults engage in at least 150 minutes of moderate activity per week for general health benefits. We compared **physical activity** levels before and after a breast cancer diagnosis and found that 65% of the women in our study failed to meet national recommendations for physical activity levels after a breast cancer diagnosis, compared to 39% before diagnosis. **Message:** *More work needs to be done to promote physical activity, particularly after a breast cancer diagnosis and treatment.*

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