

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 and the National Cancer Institute

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

Follow Up Issue #3

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Study Contact Information

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

Congratulations, CBCS Study participants!

You've made it through the in-person interview and two follow-up telephone calls with CBCS staff over the past two years. For our third follow-up, we will not contact participants by telephone. Rather, we just want to share our newsletter, some study updates, and our thanks for all your help with this important research.

We are very excited to report that we are having amazing success in reaching over 97% of our study participants for follow-up. These participation rates are phenomenal, thanks to all of you! We are currently compiling the information collected from the women in our study in order 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 hope you will enjoy this edition of the CBCS Newsletter. We have received submissions from several participants and breast cancer survivors which are showcased in the “Survivor Diaries” and “Rhymes of Recovery” sections of the newsletter. Also included is an article on hormonal therapy, sometimes called endocrine therapy, which we hope you will find interesting and informative. Tucked inside this newsletter, you will find a form listing the current contact information we have on file for you. We would be grateful if you would **update your information** and **return the form** in the **enclosed pre-paid envelope**, so that we can reach you for future follow-ups.

We hope to share news about our findings with you towards the end of the study. In the meantime, please feel free to contact us with questions or concerns. You can also find information on our website at cbcs.med.unc.edu. Thank you again for being a part of this important research. Remember, we could not do it without you!



Recruitment Progress. By October 2013, 3000 women will be enrolled. Our ginkgo sapling has grown into a beautiful, full-grown ginkgo tree. Thanks for your participation!

Hormonal Therapy

What is hormonal therapy?

Breast cancers that have estrogen receptors are called “ER positive” (ER+) cancers. ER+ breast cancers need estrogen, a type of female hormone, to grow. Hormonal therapy, also known as endocrine therapy, is treatment that fights ER+ breast cancer by preventing the cancer from growing, multiplying, and spreading. This treatment may also be used to treat advanced-stage, or metastatic, ER+ breast cancer. The four most common hormonal therapy medications are Tamoxifen, Arimidex, Femara, and Aromasin. These hormonal therapy pills can be given during or after other breast cancer treatments such as chemotherapy and radiation.

How does hormonal therapy work?

When estrogen attaches to its receptor on the ER+ cancer cell, signals are sent telling the cancer cell to grow and multiply. This can increase the chance of the breast cancer returning. Hormonal therapy prevents cancer growth and spread by lowering or stopping estrogen in the body. Hormonal therapy medicine works in two ways:

- 1) Tamoxifen, an anti-estrogen, blocks estrogen’s receptor on the cancer cell, which prevents estrogen from attaching to it. This stops the signals that tell the cancer cell to grow. Without these growth signals, the cancer cells cannot multiply and can die, lowering the risk of breast cancer recurrence. Women of any age can use Tamoxifen.
- 2) Arimidex, Femara, and Aromasin are aromatase inhibitors, or medicines that block estrogen production to lower its levels in the body. Less available estrogen means the cancer cells have a decreased chance of growing or metastasizing. Arimidex, Femara, and Aromasin are only used for women who are post-menopausal.

For More Information on Hormonal Therapy:

- **Breast Cancer Resource Directory, 4th Edition pages 29-30 or www.bcresourcedirectory.org. To obtain a paper copy, call 800.514.4860**
- **<http://www.breastcancer.org/treatment/hormonal/>**
- **<http://www.cancer.gov/cancertopics/pdq/treatment/breast/Patient/page5>**

For pre-menopausal women, there are medications that can temporarily stop estrogen production in the ovaries. To permanently stop estrogen production, ovaries can be surgically removed, a procedure known as an oophorectomy. Both of these types of treatments can also be considered hormonal therapy.

Is hormonal therapy right for me?

Hormonal therapy is used to treat only hormone receptor positive breast cancer. In other words, if your type of cancer is estrogen receptor positive (ER+), the cancer cells have receptors that respond to circulating estrogen and use it to grow and multiply. For ER+ breast cancer, hormonal therapy can decrease the chance of your cancer from growing and recurring.

Ways to help you take your hormonal therapy regularly:

- ☑ Write down a copy of your treatment plan
- ☑ Keep a medicine diary
- ☑ Take your medicine at the same time each day
- ☑ Use an alarm clock
- ☑ Plan ahead if you will be away from home

What to expect when taking hormonal therapy

Sometimes, but not always, hormonal therapy can cause side effects like hot flashes, night sweats, and bone and joint pain. More serious side effects include heart problems, bone loss, and blood clots. If you are experiencing side effects, don’t let this prevent you from getting the benefits of hormonal therapy. Talk to your doctor about taking supplements or medicine to reduce the side effects, changing the dose, or switching to another medication.

Since hormonal therapy is used to decrease the risk of recurrence, the medication is usually taken for a long period of time (5 to 10 years). To get the best results, it is very important to take your hormonal therapy regularly. There are many ways to stay on track with your treatment (see *box at left*).

Do whatever works for you, as long as you stay on track!

SURVIVOR *Diaries*

*An excerpt from a letter submitted by
P.B., Mecklenburg County, NC:*

Today I sit here with tears in my eyes, writing this letter to my team of doctors, nurses, surgeons, chemo techs, radiation techs, and down to the cleaning lady that smiled at me every morning when I was feeling like my world was about to end. Two years ago, in February, I received the devastating news that I had bilateral breast cancer at 36 years old. Immediately I thought, "Am I going to die and leave my children behind?" After two weeks of crying and waddling in self-pity, my youngest son came in my room and asked me if I was going to die. I didn't have an answer for him but I got on my knees and asked the Lord to please spare my life. At that point I was able to get up out of my dark hole of sorrow. I found the answer. Hell no! I am not going to die!



The first person I saw was my surgeon. He could tell I was confused. "A deer in headlights" is what he called me. He explained my options and gave me time to think about what I wanted to do. He was really patient and always looked me right in my eyes to give it to me straight. He referred me to an oncologist. I didn't know what to expect. Chemo, to me, was such a scary, ugly thing that made you bald and sick. Well, my first appointment was with the oncology nurse. She was the sweetest person. She gave me a hug when she noticed that I was sitting there with my head down. She assured me that chemotherapy had advanced in the last few years and I shouldn't have to be as sick, but she couldn't help me with the hair loss part. Then my oncologist walked in; she was slim and beautiful with the best set of white teeth I had ever seen. You are probably thinking, why would I talk about her teeth? Well, the moment I met her and saw the smile on her face, I knew everything would be okay. At my last chemo treatment, the ladies presented me with a graduation certificate and blew bubbles at me. We all hugged and they all said they hoped to never see me again unless I am coming to visit. My next step was surgery. I had decided to keep my breast. My surgeon was awesome! He removed all the cancer with very little scarring. Next on the journey was radiation, for six weeks, five days a week. My radiation oncologist made a personal phone call to me to set up my therapy. That really impressed me. The radiation tech always made sure I finished my treatments on time to get to work as soon as possible. She knew that having cancer doesn't stop the bills from coming!

I will take a daily pill called Tamoxifen [see *Hormonal Therapy*, pg. 2] for the next five years. I feel great and look forward to spending a very merry Christmas with my children, without cancer being the subject. I couldn't let another day go by without letting my team of doctors know how much each and every one of them mean to me. Without them and the help of the good Lord, I don't know where I would be.

*An excerpt from a letter submitted by
J.B., Durham County, NC:*

I was doing a breast exam last March and found a mass. I was so devastated that night. I got up the next morning and made an appointment. I went for a mammogram and ultrasound, which were sent to the hospital for the reading. The hospital could not read the images, therefore I took another mammogram and ultrasound. The radiologist said, "You have cancer." I said, "How do you know?" He said "I see." The size of the mass was 2.3 centimeters. I was so surprised because another hospital said that it was a hematoma mass. I am a 53-year-old female with a history of breast cancer. I am receiving chemotherapy. I do have a cyst on my liver, but it is benign. I decided to do the Jeanne Hopkins Lucas Study to help other women of all races with breast cancer.

**If you'd like to submit your
own story and photo,
please mail to:**

Carolina Breast Cancer Study
UNC-Chapel Hill, LCCC,
Attn: Survivor Diaries, Rm 332
CB # 7294
Chapel Hill, NC 27599-7294

Or email:
cbcs@unc.edu

Rhymes of Recovery

A Year Ago Today

By J.B., Forsyth County, NC

A year ago today, I got that dreaded call.
 It's breast cancer. But it's early and it's small.
 My heart skipped a beat, probably a few;
 And my eyes did bawl – fearing – this unwelcome journey,
 so raw.
 This is SO not fair!
 But then calmness came over me, like a breath of fresh air.
 God spoke and I listened... He said... "I am with you;"
 He then lifted my burden so fresh and so new.
 I knew in that moment, I'd be fine,
 just as sure as the sun brightly shines.
 I called my husband to share the breaking news.
 I'm sorry dear. But it is true.

Please stay at work and finish your day,
 for I KNOW, I'll be ok.
 I told our boys without much ado;
 Business as usual, and back to school, too.
 Now the tumor is out, and the scar is there
 to remind me of my... cancer scare.
 I see the tiny tattoos, and feel the tightness in my chest,
 But what that tells me is... I've been blessed.
 Thank you my husband for loving me;
 for cooking, cleaning and caring with mounds of glee.
 Thank you my sons for keeping it real.
 By keeping life normal, I was able to heal.
 Thank you Lord for holding my hand and walking with me,
 through this journey... of reality.

Tried Not to Become an Advocate

By C.A., Alamance County, NC

Tried not to become an advocate.
 Resisted as long as I could.
 Tried to stick my head in the sand
 And fill my ears with wood.

Tried not to find the hard knot under my arm.
 Tried not to think of my mother with alarm.
 Tried not to think of the breast cancer that took her away.
 Tried not to think of the knot that continued to stay.

Tried not to be afraid when I had a mammogram.
 Tried not to listen when the Radiologist said, "Ma'am
 please sit down."
 Tried not to hear "Advise having a surgeon check
 the enlarged lymph node."
 Tried not to think of my two year old.

Tried not to be impatient while as a patient I waited
 For over an hour for the surgeon to take two minutes
 To get my history, three minutes more for an exam,
 Then slam, "Nothing wrong with you Ma'am,"
 Bam, "Fifty dollars please! Thank you Ma'am,"
 and I was out the door!

Tried not to hear myself say, "I need another doctor
 To make sure this knot is not cancer!"
 Tried not to see the second surgeon but did it anyway
 So glad to hear him say, "You're okay!"
 And I was on my way!

Tried not to feel a lump in my breast bending over
 in the shower six months later.
 Tried not to feel the knot under my arm was greater.
 Tried not to hear surgeon #3 tell me, "The entire breast
 would have to be taken."

Tried not to cry about surgery and think I wouldn't awaken.
 Tried not to show my pain to my husband and child.
 Tried not to let my emotions run wild!

Tried not to believe I would die at 42?
 When told 14 malignant lymph nodes were found, too!
 Tried not to laugh when I saw myself without my breast
 for the very first time.
 But I looked so one-sided and flat,
 I didn't ask why or cry—just said, "That's that!"

Tried not to think about 4 months of chemo, then a bone
 marrow transplant to be followed by six weeks of radiation.
 Just started to enjoy everything in God's creation!

Tried not to be shocked when my hair began to fall.
 Just let my daughter help literally pull it all 'til I was bald.
 Tried not to show my disgust when I passed a mirror.
 Just tried to be glad I was alive and think, "Survive! Survive!"

Tried not to remember the "Slash, poison, burn"
 to make it not return.
 Tried not to let the pain or weight gain get to me.
 Tried not to be angry
 when I met so many other women like me!

Tried not to think of my daughter who looks so much like me
 and has blue eyes of her grandmother
 Learn she might follow our path of "Slash, poison, burn!"
 No! It won't be her turn!

So I became an advocate.
 Resisted as long as I could.
 I will not stick my head in the sand
 Or fill my ears with wood!