

Carolina Breast Cancer Study 3

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FOLLOW UP #6 Mail-In Survey

(Appendix B-2)

YOUR NAME: _____

Date completed: _____

Thank you for agreeing to complete this set of questions and mail it back to us in the enclosed pre-paid envelope. The goal of this study is to collect information that may help us to better understand how breast cancer has impacted your life. There are no right or wrong answers to any of these questions. You should just report what you have experienced.

Your participation is voluntary, and all the information collected will be kept completely confidential. If you should come to any question that you do not want to answer, just skip it and go on to the next question.

You will receive a check in the amount of Twenty-Five Dollars (\$25) within three weeks of returning this completed survey.

Questions? Call our toll-free telephone number: 1-866-927-6920.

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Date Completed: ___ ___ / ___ ___ / ___ ___ ___ ___

ID:

SECTION A: QUESTIONS ABOUT YOUR HEALTH

The following section includes questions about your physical well-being and your quality of life since your diagnosis of breast cancer. Some of the questions are of a personal nature.

Below is a list of statements that other people with breast cancer have said are important. By **circling one (1) number per line**, please indicate how true each statement has been for you during the past 7 days.

PHYSICAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very Much
A1.	I have a lack of energy.	0	1	2	3	4
A2.	I have nausea.	0	1	2	3	4
A3.	Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
A4.	I have pain.	0	1	2	3	4
A5.	I am bothered by side effects of treatment.	0	1	2	3	4
A6.	I feel ill.	0	1	2	3	4
A7.	I am forced to spend time in bed.	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

SOCIAL/FAMILY WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
A8.	I feel close to my friends.	0	1	2	3	4
A9.	I get emotional support from my family.	0	1	2	3	4
A10.	I get support from my friends.	0	1	2	3	4
A11.	My family has accepted my illness.	0	1	2	3	4
A12.	I am satisfied with family communication about my illness.	0	1	2	3	4
A13.	I feel close to my partner (or the person who is my main support).	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please skip to A15</i>		Not at all	A little bit	Some-what	Quite a bit	Very much
A14.	I am satisfied with my sex life.	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

EMOTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very Much
A15.	I feel sad.	0	1	2	3	4
A16.	I am satisfied with how I am coping with my illness.	0	1	2	3	4
A17.	I am losing hope in the fight against my illness.	0	1	2	3	4
A18.	I feel nervous.	0	1	2	3	4
A19.	I worry about dying.	0	1	2	3	4
A20.	I worry that my condition will get worse.	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

FUNCTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very Much
A21.	I am able to work (include work at home).	0	1	2	3	4
A22.	My work (include work at home) is fulfilling.	0	1	2	3	4
A23.	I am able to enjoy life.	0	1	2	3	4
A24.	I have accepted my illness.	0	1	2	3	4
A25.	I am sleeping well.	0	1	2	3	4
A26.	I am enjoying the things I usually do for fun.	0	1	2	3	4
A27.	I am content with the quality of my life right now.	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

ADDITIONAL CONCERNS		Not at all	A little bit	Some-what	Quite a bit	Very Much
A28.	I have been short of breath.	0	1	2	3	4
A29.	I am self-conscious about the way I dress.	0	1	2	3	4
A30.	One or both of my arms are swollen or tender.	0	1	2	3	4
A31.	I feel sexually attractive.	0	1	2	3	4
A32.	I am bothered by hair loss.	0	1	2	3	4
A33.	I worry that other members of my family might someday get the same illness I have.	0	1	2	3	4
A34.	I worry about the effect of stress on my illness.	0	1	2	3	4
A35.	I am bothered by a change in weight.	0	1	2	3	4
A36.	I am able to feel like a woman.	0	1	2	3	4
A37.	I have certain parts of my body where I experience significant pain.	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

ADDITIONAL CONCERNS (cont'd)		Not at all	A little bit	Some-what	Quite a bit	Very much
A38.	I have hot flashes.	0	1	2	3	4
A39.	I have cold sweats.	0	1	2	3	4
A40.	I have night sweats.	0	1	2	3	4
A41.	I have vaginal discharge.	0	1	2	3	4
A42.	I have vaginal itching/irritation.	0	1	2	3	4
A43.	I have vaginal bleeding or spotting.	0	1	2	3	4
A44.	I have vaginal dryness.	0	1	2	3	4
A45.	I have pain or discomfort with intercourse.	0	1	2	3	4
A46.	I have lost interest in sex.	0	1	2	3	4
A47.	I have gained weight.	0	1	2	3	4
A48.	I feel lightheaded (dizzy).	0	1	2	3	4
A49.	I have been vomiting.	0	1	2	3	4
A50.	I have diarrhea.	0	1	2	3	4
A51.	I get headaches.	0	1	2	3	4
A52.	I feel bloated.	0	1	2	3	4
A53.	I have breast sensitivity/tenderness.	0	1	2	3	4
A54.	I have mood swings.	0	1	2	3	4
A55.	I am irritable.	0	1	2	3	4
A56.	I have pain in my joints.	0	1	2	3	4

Many women who have had breast cancer take endocrine therapy pills (also known as hormonal therapy or anti-estrogen therapy) to help keep breast cancer from coming back. Specific names of these hormonal therapy drugs are Tamoxifen, Femara (or Letrozole), Aromasin (or Exemestane), and Arimidex (or Anastrozole).

A57. Has your doctor **ever** prescribed hormonal therapy pills for you to help keep your breast cancer from coming back?

- ____ 1. YES
- ____ 2. NO → (Go to pg. 9, Question A74)
- ____ 9. I DON'T KNOW

A58. **Since your breast cancer diagnosis**, have you **ever** taken hormonal therapy pills to help keep your breast cancer from coming back?

- ____ 1. YES
- ____ 2. NO → (Go to Pg. 9, Question A74)

A59. At this time, are you taking hormonal therapy pills?

- ____ 1. Yes, I'm taking them every day as prescribed by my doctor
- ____ 2. Yes, I'm taking them, but not every day as prescribed by my doctor
- ____ 3. No, I stopped taking those pills
 - 3a. If you stopped taking them (which is fine), please explain: _____
 - _____
 - _____

A60. Over the past **two** weeks, how many days did you miss your hormonal therapy pills? (*Mark an "X" in front of only **ONE** answer*)

- ____ 0. I didn't miss any days
- ____ 1. I missed 1 day
- ____ 2. I missed 2 days
- ____ 3. I missed 3 days
- ____ 4. I missed 4 days
- ____ 5. I missed 5 or more days
- ____ 6. Not applicable. I am no longer taking hormone therapy pills.

A61. For how many total months or years since your breast cancer diagnosis did you take or have you taken hormonal therapy pills? (If less than one year, please enter the number of months. If one year or more, please enter the number of years and months.)

How many years? ____ ____ How many months? ____ ____

Please answer the following questions, thinking about the time that you were taking hormonal therapy pills, regularly or irregularly. (Even if you have stopped taking the pills, please reflect on your experience while you were taking them.)

A62. While you were taking them, how regularly did you take these hormonal therapy pills? (*Mark an "X" in front of only ONE answer*)

- ____ 1. Very regularly (Daily/almost daily or 80-100% of the time)
- ____ 2. Somewhat regularly (50-80% of the time)
- ____ 3. Not very regularly (Less than 50% of the time)

A63. Over an average two week period, how many days did you miss your hormonal therapy pills? (*Mark an "X" in front of only ONE answer*)

- ____ 0. I didn't miss any days
- ____ 1. I missed 1 day
- ____ 2. I missed 2 days
- ____ 3. I missed 3 days
- ____ 4. I missed 4 days
- ____ 5. I missed 5 or more days

A64. Please mark an “X” in front of the problem(s) or symptom(s) listed below that you have experienced since your breast cancer diagnosis that you believe are or were caused by your hormonal therapy pills:

- | | |
|---|---|
| <input type="checkbox"/> a. Hot flashes | <input type="checkbox"/> k. Lightheadedness (dizzy) |
| <input type="checkbox"/> b. Cold sweats | <input type="checkbox"/> l. Vomiting |
| <input type="checkbox"/> c. Night sweats | <input type="checkbox"/> m. Diarrhea |
| <input type="checkbox"/> d. Vaginal discharge | <input type="checkbox"/> n. Headaches |
| <input type="checkbox"/> e. Vaginal itching/irritation | <input type="checkbox"/> o. Bloating |
| <input type="checkbox"/> f. Vaginal bleeding or spotting | <input type="checkbox"/> p. Breast sensitivity/tenderness |
| <input type="checkbox"/> g. Vaginal dryness | <input type="checkbox"/> q. Mood swings |
| <input type="checkbox"/> h. Pain or discomfort with intercourse | <input type="checkbox"/> r. Irritability |
| <input type="checkbox"/> i. Lost interest in sex | <input type="checkbox"/> s. Pain in my joints |
| <input type="checkbox"/> j. Weight gain | |

A65. Taking pills every day can be hard. For you, has sticking to your hormonal therapy treatment plan been... *(Mark an “X” in front of only ONE answer)*

- 1. Very hard
- 2. Somewhat hard
- 3. Not hard at all

A66. Think about the whole process of taking these hormonal therapy pills—from filling the prescription to taking the pills every day and putting up with the side effects from them. Do you think... *(Mark an “X” in front of only ONE answer)*

- 1. The good outweighs the bad
- 2. The good and bad are equal
- 3. The bad outweighs the good

For you, during the last year that you took or have been taking hormonal therapy pills, how often has it been true that you missed your hormonal therapy pills because...

<i>(Circle one number per line)</i>		Often true for you	Sometimes true for you	Practically never true for you
A67.	The pills are too expensive.	1	2	3
A68.	You just forget to take them.	1	2	3
A69.	You don't get around to refilling the prescription.	1	2	3
A70.	The side effects of these pills are too hard to deal with.	1	2	3
A71.	Taking medication for a long time is not healthy.	1	2	3

A72. Suppose you took all your hormone therapy pills as prescribed. What do you think the chance would be that your cancer would ever come back? *(Mark an "X" in front of only **ONE** answer)*

- ___ 1. Very low chance
- ___ 2. Low chance
- ___ 3. Moderate chance
- ___ 4. High chance
- ___ 5. Very high chance

A73. Suppose you stopped taking these pills as prescribed. What do you think would happen to your chances of your breast cancer coming back? *(Mark an "X" in front of only **ONE** answer)*

- ___ 1. My chances would go up a lot
- ___ 2. My chances would go up a little
- ___ 3. My chances would not really change

These next questions ask about your symptoms as well as your ability to perform certain activities. Please answer every question, based on your condition in the last week, by circling the appropriate number.

If you did not have the opportunity to perform an activity in the past week, please make your best estimate of which response would be the most accurate.

It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.

<i>(Circle one number per line)</i>		NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
A79.	Open a tight or new jar	1	2	3	4	5
A80.	Do heavy household chores (e.g., wash walls, wash floors)	1	2	3	4	5
A81.	Carry a shopping bag or briefcase	1	2	3	4	5
A82.	Wash your back	1	2	3	4	5
A83.	Use a knife to cut food	1	2	3	4	5
A84.	Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.)	1	2	3	4	5

<i>(Circle one number per line)</i>		NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
A85.	During the past week, to what extent have arm, shoulder or hand problems interfered with your normal social activities with family, friends, neighbors or groups?	1	2	3	4	5

		NOT LIMITED AT ALL	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
<i>(Circle one number per line)</i>						
A86.	During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem?	1	2	3	4	5

Please rate the severity of the following symptoms in the last week.

		NONE	MILD	MODERATE	SEVERE	EXTREME
<i>(Circle one number per line)</i>						
A87.	Arm, shoulder or hand pain	1	2	3	4	5
A88.	Tingling (pins and needles) in your arm, shoulder or hand	1	2	3	4	5

		NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
<i>(Circle one number per line)</i>						
A89.	During the past week, how much difficulty have you had sleeping because of pain in your arm, shoulder or hand?	1	2	3	4	5

The following questions ask about the impact of your arm, shoulder or hand problem on your ability to work. If you are not working outside of the home, then please tell us about any difficulties that you have had with housework or other tasks around your home.

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

Did you have any difficulty:		NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
A90.	Using your usual technique for your work?	1	2	3	4	5
A91.	Doing your usual work because of arm, shoulder or hand pain?	1	2	3	4	5
A92.	Doing your work as well as you would like?	1	2	3	4	5
A93.	Spending your usual amount of time doing your work?	1	2	3	4	5

The following section includes a list of statements that other people with breast cancer have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

(Circle one number per line)		Not at all	A little bit	Some-what	Quite a bit	Very much
A94.	I feel peaceful.	0	1	2	3	4
A95.	I have a reason for living.	0	1	2	3	4
A96.	My life has been productive.	0	1	2	3	4
A97.	I have trouble feeling peace of mind.	0	1	2	3	4
A98.	I feel a sense of purpose in my life.	0	1	2	3	4
A99.	I am able to reach down deep into myself for comfort.	0	1	2	3	4
A100.	I feel a sense of harmony within myself.	0	1	2	3	4
A101.	My life lacks meaning and purpose.	0	1	2	3	4
A102.	I find comfort in my faith or spiritual beliefs.	0	1	2	3	4
A103.	I find strength in my faith or spiritual beliefs.	0	1	2	3	4
A104.	My illness has strengthened my faith or spiritual beliefs.	0	1	2	3	4
A105.	I know that whatever happens with my illness, things will be okay.	0	1	2	3	4

Below is a list of statements that other people with breast cancer have said are important. By **circling one (1) number per line**, please indicate how true each statement is for you.

<i>(Circle one number per line)</i>		Not at all	A little bit	Some-what	Very much	
A106.	I worry about future diagnostic tests, such as mammograms and CT scans.	1	2	3	4	
A107.	I worry about another type of cancer.	1	2	3	4	
A108.	I worry about my breast cancer coming back.	1	2	3	4	
A109.	I worry about dying.	1	2	3	4	
A110.	I worry about my health.	1	2	3	4	
						Not Applicable
A111.	I worry about my children's health.	1	2	3	4	5

THANK YOU FOR COMPLETING THIS SECTION.

YOU ARE NOW HALF-WAY THROUGH THE SURVEY.

**IF YOU NEED A BREAK, THIS IS A GOOD POINT TO STOP
BEFORE COMPLETING THE SURVEY.**

SECTION B: PHYSICAL ACTIVITY

On a typical **WEEKDAY (Monday, Tuesday, Wednesday, Thursday or Friday)**, how much time do you spend (from when you wake up until you go to bed) doing the following?

(Circle one number per line)

	None	Less than 1 Hour	1-2 Hours	3-4 Hours	5-6 Hours	7-8 Hours	9-10 Hours	11-12 Hours	13 or More Hours
B1. Sitting, watching television or movies (including DVDs and online)	0	1	2	3	4	5	6	7	8
B2. Sitting, using a computer, laptop, or tablet (Internet, office work, emails, paying bills, etc.)	0	1	2	3	4	5	6	7	8
B3. Driving a car or sitting in a bus or train	0	1	2	3	4	5	6	7	8

On a typical **WEEKEND DAY (Saturday or Sunday)**, how much time do you spend (from when you wake up until you go to bed) doing the following?

(Circle one number per line)

	None	Less than 1 Hour	1-2 Hours	3-4 Hours	5-6 Hours	7-8 Hours	9-10 Hours	11-12 Hours	13 or More Hours
B4. Sitting, watching television or movies (including DVDs and online)	0	1	2	3	4	5	6	7	8
B5. Sitting, using a computer, laptop, or tablet (Internet, office work, emails, paying bills, etc.)	0	1	2	3	4	5	6	7	8
B6. Driving a car or sitting in a bus or train	0	1	2	3	4	5	6	7	8

B7. Think about the **WALKING** you do **OUTSIDE THE HOME**. How often do you walk outside the home for more than 10 minutes without stopping? *(Mark an "X" in front of only ONE answer)*

- 1. Rarely or never
- 2. 1 to 3 times each MONTH
- 3. 1 time each WEEK
- 4. 2 to 3 times each WEEK
- 5. 4 to 6 times each WEEK
- 6. 7 or more times each WEEK

B8. When you walk outside the home for more than 10 minutes without stopping, for how many minutes do you usually walk? *(Mark an "X" in front of only ONE answer)*

- 1. None (I never walk outside the home for more than 10 minutes without stopping)
→ (If None, Go to Question B10)
- 2. Less than 20 minutes
- 3. 20 to 39 minutes
- 4. 40 to 59 minutes
- 5. 1 hour or more

B9. What is your usual speed? *(Mark an "X" in front of only ONE answer)*

- 1. Casual strolling or walking (less than 2 miles an hour)
- 2. Average or normal (2-3 miles an hour)
- 3. Fairly fast (3-4 miles an hour)
- 4. Very fast (more than 4 miles an hour)
- 9. Don't Know

B10. NOT INCLUDING WALKING outside the home, how often each week (7 days) do you usually do the exercises below?

	None	1 Day per WEEK	2 Days per WEEK	3 Days per WEEK	4 Days per WEEK	5 or more Days per WEEK
<i>(Circle one number per line)</i>						
B10a. STRENUOUS OR VERY HARD EXERCISE (You work up a sweat and your heart beats fast) For example, aerobics, aerobic dancing, jogging, tennis, swimming laps. →	0	1	2	3	4	5
B10b. How long do you usually exercise like this (strenuous) at one time? <i>(Mark an "X" on the line next to only ONE answer)</i>	_____ 1. Less than 20 minutes _____ 2. 20-39 minutes _____ 3. 40-59 minutes _____ 4. 1 hour or more					
B11a. MODERATE EXERCISE (Not exhausting) For example, biking outdoors, using an exercise machine (like stationary bike or treadmill), calisthenics, easy swimming, popular or folk dancing. →	0	1	2	3	4	5
B11b. How long do you usually exercise like this (moderate) at one time? <i>(Mark an "X" on the line next to only ONE answer)</i>	_____ 1. Less than 20 minutes _____ 2. 20-39 minutes _____ 3. 40-59 minutes _____ 4. 1 hour or more					
B12a. MILD EXERCISE For example, slow dancing, bowling, golf →	0	1	2	3	4	5
B12b. How long do you usually exercise like this (mild) at one time? <i>(Mark an "X" on the line next to only ONE answer)</i>	_____ 1. Less than 20 minutes _____ 2. 20-39 minutes _____ 3. 40-59 minutes _____ 4. 1 hour or more					

SECTION C: USE OF NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)

Sub-Section 1. Prescription NSAIDS

The following questions ask you about **prescription** medications you may have taken for pain or inflammation, also known as non-steroidal anti-inflammatory drugs, or NSAIDs. Conditions that are treated with these medications include: arthritis; menstrual cramps; headaches; injuries like sprains, pulled muscles, or fractures; surgery or dental procedures; or back pain.

We are interested in any of these medications you have taken since your breast cancer diagnosis, whether you have taken them regularly or just once in a while.

Some examples of **prescription** NSAIDs include:

Celecoxib (Celebrex)	Meloxicam (Mobic)
Diclofenac (Arthrotec, Cataflam, Voltaren)	Mefenamic acid (Ponstel)
Diflunisal (Dolobid)	Nabumetone (Relafen)
Etodolac (Lodine)	Naproxen (Naprelan, Naprosyn, Anaprox)
Fenoprofen (Nalfon)	Oxaprozin (Daypro)
Flurbiprofen (Ansaid)	Prioxicam (Feldene)
Ibuprofen (Motrin)	Salsalate (Disalcid, Amigesic)
Indomethacin (Indocin)	Sulindac (Clinoril)
Ketoprofen (Orudis, Oruvail)	Tolmentin (Tolectin)
Ketorolac (Toradol)	

C1. Since your breast cancer diagnosis, have you taken **prescription** NSAIDs for pain or inflammation?

___ 1. YES ___ 2. NO → (Go to pg. 18, **Sub-Section 2: Non-Prescription NSAIDS**)

C2. Overall, for how many months or years since your breast cancer diagnosis have you taken these **prescription** NSAIDs? *(If less than one year, please enter the number of months. If one year or more, please enter the number of years and months.)*

How many years? ___ ___

How many months? ___ ___

C3. While you were taking them, how regularly did you take these **prescription** NSAIDs?

- ___ 1. Daily/almost daily
___ 2. More than 14 days per month
___ 3. 8 to 14 days per month
___ 4. 2 to 7 days per month
___ 5. 1 day per month or less

C4. For what condition(s) did you take these **prescription** NSAIDs? (*Mark an "X" in front of **all that apply***)

- ___ a. Arthritis, bursitis, rheumatism
- ___ b. Menstrual cramps
- ___ c. Surgical pain
- ___ d. Back pain
- ___ e. Headache
- ___ f. Other - *Please specify:* 1. _____
2. _____
3. _____

C5. What is the name of the **prescription** NSAID(s) that you took most commonly? (*You may include up to **3** answers*)

- Name of drug(s): 1. _____
2. _____
3. _____

Sub-Section 2. Non-Prescription NSAIDS

The next questions deal with **non-prescription (over the counter)** NSAIDs. We are interested in any of these medications you have taken since your breast cancer diagnosis, whether you have taken them regularly or just once in a while.

Some examples of **non-prescription** NSAIDs include:

Naproxen (Aleve)
Aspirin (Bayer, Bufferin, Excedrin, Vanquish, Ascriptin, Ecotrin)
Ibuprofen (Advil, Motrin, Nuprin)
Goody's Powder
BC Powder

C6. Since your breast cancer diagnosis, have you taken **non-prescription** NSAIDs for pain or inflammation? (**PLEASE DO NOT INCLUDE TYLENOL OR ACETAMINOPHEN**)

- ___ 1. YES → (Go to next page, Question C7)
- ___ 2. NO → (Go to pg. 20, Section D)

C7. Overall, for how many months or years since your breast cancer diagnosis have you taken these **non-prescription** NSAIDs? *(If less than one year, please enter the number of months. If one year or more, please enter the number of years and months.)*

How many years? ____ ____

How many months? ____ ____

C8. While you were taking them, how regularly did you take these **non-prescription** NSAIDs?

____ 1. Daily/almost daily

____ 2. More than 14 days per month

____ 3. 8 to 14 days per month

____ 4. 2 to 7 days per month

____ 5. 1 day per month or less

C9. For what condition(s) did you take these **non-prescription** NSAIDs? *(Mark an "X" in front of **all that apply**)*

____ a. Arthritis, bursitis, rheumatism

____ b. Menstrual cramps

____ c. Surgical pain

____ d. Back pain

____ e. Headache

____ f. Other - *Please specify:* 1. _____

2. _____

3. _____

C10. What is the name of the **non-prescription** NSAID(s) that you took most commonly? *(You may include up to 3 answers)*

Name of drug(s): 1. _____

2. _____

3. _____

SECTION D: FINANCIAL IMPACT

For each question, please mark an “X” under the appropriate answer.

	Has having cancer caused you to:	(1) YES	(2) NO	(9) Don't know
D1.	Apply for unemployment benefits?			
D2.	Apply for long-term disability?			
D3.	Apply for medical financial assistance programs to help pay for cancer care?			
D4.	Borrow money from friends or family to pay for cancer care?			
D5.	Sell your house or property to pay for cancer care?			
D6.	Miss bill payments to pay for cancer care?			
D7.	(You or your spouse/partner to) take a second job to pay for cancer care?			
D8.	Use up all or a portion of your savings to pay for cancer care?			
D9.	Borrow money from financial institutions (e.g., credit, taking out a second mortgage, etc.) to pay for cancer care?			
D10.	Declare bankruptcy?			
D11.	Have increases in how much you pay for health insurance?			
D12.	Exceed health insurance covered benefits?			
D13.	Lose or be denied health insurance coverage?			

Since being diagnosed with breast cancer, **have you used any of the following strategies to help cope with the various costs of your cancer care** (for example, clinic visits, medical equipment, or other medical expenses) or for your **prescriptions**?

		(1)	(2)	(9)
	<i>(Mark an "X" under one answer per line)</i>	YES	NO	Don't know
D14.	Missed clinic or chemotherapy appointments to save money			
D15.	Spread out clinic or chemotherapy appointments to save money			
D16.	Reduced spending on basics like food or clothing in order to pay for your cancer care			
D17.	Reduced spending on leisure activities like vacations, eating out, or movies in order to pay for your cancer care			
D18.	Chosen one doctor over another because of cost			
D19.	Not had a recommended procedure because of cost			
D20.	Not had a recommended test (like a CT scan) because of cost			
D21.	Delayed a recommended procedure because of cost			
D22.	Asked your doctor for a less expensive prescription medicine than the one the doctor had first suggested			
D23.	Used medicines prescribed for another person			
D24.	Took less than the prescribed amount of medicine to save money			
D25.	Reduced spending on basics like food or clothing in order to pay for a prescription medicine			
D26.	Filled only part of a prescription because it cost too much			
D27.	Didn't fill a prescription because it cost too much			
D28.	Purchased an over-the-counter product to replace a more costly prescription drug			
D29.	Enrolled in an assistance program to help pay for prescription medicines (not including insurance or Medicare/Medicaid)			
D30.	Shopped around at pharmacies to get a medication at the lowest price			
D31.	Purchased medication from another country to save costs			
D32.	Borrowed money or used credit cards to pay for your medicines			
D33.	Requested free prescription medicine samples from your doctor			

By circling one (1) number per line, please indicate how true each statement has been for you since your breast cancer diagnosis.

<i>(Circle one number per line)</i>		Not at all	A little bit	Some-what	Quite a bit	Very Much
D34.	I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment.	0	1	2	3	4
D35.	My out-of-pocket medical expenses are more than I thought they would be.	0	1	2	3	4
D36.	I worry about the financial problems I will have in the future as a result of my illness or treatment.	0	1	2	3	4
D37.	I feel I have no choice about the amount of money I spend on care.	0	1	2	3	4
D38.	I am frustrated that I cannot work or contribute as much as I usually do.	0	1	2	3	4
D39.	I am satisfied with my current financial situation.	0	1	2	3	4
D40.	I am able to meet my monthly expenses.	0	1	2	3	4
D41.	I feel financially stressed.	0	1	2	3	4
D42.	I am concerned about keeping my job and income, including work at home.	0	1	2	3	4
D43.	My cancer or treatment has reduced my satisfaction with my present financial situation.	0	1	2	3	4
D44.	I feel in control of my financial situation.	0	1	2	3	4

The following questions ask for information about your work history since your breast cancer diagnosis, and about your household.

D45. Are you currently working for pay? This includes full-time or part-time paid work, as well as self-employment.

_____ 1. YES

_____ 2. NO

D46. At any time since your breast cancer diagnosis, have you left a job due to breast cancer?

____ 2. NO

____ 1. YES → **D46a.** If yes, why? (Mark an "X" in front of **all that apply**)

____ a. I retired early

____ b. I was laid off or fired

____ c. I stopped working because my job was too physically demanding

____ d. I stopped working because my job was too mentally demanding

____ e. Other - Please specify: _____

D47. Have concerns about health insurance kept you in a job since having breast cancer?

____ 1. YES

____ 2. NO

D48. What is your present marital status? (Mark an "X" in front of only **ONE** answer)

____ 1. I have never married or lived as married

____ 2. I am married, or living as married

____ 3. I am widowed

____ 4. I am separated, divorced, or no longer living as married

____ 9. I prefer not to answer

D49. Last year, what was your total family income range, before taxes?

(Mark an "X" in front of only **ONE** answer)

____ 0. Less than \$5,000

____ 1. \$5,000 to \$10,000

____ 2. \$10,001 to \$15,000

____ 3. \$15,001 to \$20,000

____ 4. \$20,001 to \$30,000

____ 5. \$30,001 to \$50,000

____ 6. \$50,001 to \$100,000

____ 7. More than \$100,000

____ 8. Don't know

____ 9. Prefer not to answer

D50. How many people are supported by this income?

_____ People

(This includes anyone you are supporting, not just for tax purposes)

SECTION E: TREATMENT DECISIONS

Please think about the decision you made about whether to have **lumpectomy** (removing part of your breast) or **mastectomy** (removing all of your breast) after talking with your surgeon. Please show how you feel about these statements by **circling the number** from 1 (strongly agree) to 5 (strongly disagree). *(If you had more than one lumpectomy or mastectomy surgery, answer for whichever you think is most important.)*

		Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
<i>(Circle one number per line)</i>						
E1.	It was the right decision.	1	2	3	4	5
E2.	I regret the choice that was made.	1	2	3	4	5
E3.	I would go for the same choice if I had to do it over again.	1	2	3	4	5
E4.	The choice did me a lot of harm.	1	2	3	4	5
E5.	The decision was a wise one.	1	2	3	4	5

E6. Have you had a mastectomy?

- ___ 1. YES
- ___ 2. NO → (Go to pg. 25, Section F)
- ___ 9. Don't Know → (Go to pg. 25, Section F)

Please think about the decision you made about whether to have **breast reconstruction after mastectomy** (surgery to make a new breast shape using an implant or transfer of skin and muscle), after talking with your doctor. Please show how you feel about these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree).

		Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
<i>(Circle one number per line)</i>						
E7.	It was the right decision.	1	2	3	4	5
E8.	I regret the choice that was made.	1	2	3	4	5
E9.	I would go for the same choice if I had to do it over again.	1	2	3	4	5
E10.	The choice did me a lot of harm.	1	2	3	4	5
E11.	The decision was a wise one.	1	2	3	4	5

SECTION F: FERTILITY AND CONTRACEPTION

F1. Have you ever had surgery to remove your uterus?

____ 1. YES → a. What age? ____ ____

____ 2. NO

F2. Have you ever had surgery to remove one or both of your ovaries?

____ 2. NO

____ 1. YES → Mark an **“X”** in front of **one** answer below and indicate age at removal:

____ 1a. Both ovaries removed at the same time. → 1b. What age? ____ ____

____ 2a. Both ovaries removed at different times.

→ 2b. What age 1st ovary removed? ____ ____

→ 2c. What age 2nd ovary removed? ____ ____

____ 3a. One ovary removed → 3b. What age? ____ ____

F3. Were you still having menstrual periods at the time you were diagnosed with breast cancer (before you started treatment)?

____ 1. YES → (Go Question F4)

____ 2. NO → **STOP HERE. GO TO PG. 32, END OF SURVEY.**

F4. Did your menstrual periods stop when you were having breast cancer treatment?

____ 2. NO → (Go to Question F5)

____ 1. YES → **F4a.** Did you ever go back to having menstrual periods after your treatment?

____ 1. YES

____ 2. NO → (Go to Question F6)

F5. Are you still having menstrual periods?

____ 1. YES

____ 2. NO → **F5a.** How old were you when your menstrual periods stopped? ____ ____

F6. How old were you at the time of your breast cancer diagnosis? _____

IF YOU WERE 45 YEARS OF AGE OR OLDER AT THE TIME OF YOUR BREAST CANCER DIAGNOSIS, YOU'RE FINISHED! GO TO PG. 32, END OF SURVEY.

IF YOU WERE YOUNGER THAN 45 YEARS OLD AT THE TIME OF YOUR BREAST CANCER DIAGNOSIS, PLEASE GO TO QUESTION F7.

F7. Since your breast cancer diagnosis, have you had sexual intercourse with a man?

_____ 1. YES

_____ 2. NO → (Go to pg. 28, Question F26)

F8. Have you or your partner used any of the following birth control methods:

(Mark an "X" in the box below the appropriate answer for each question)

	(1)	(2)	
	YES	NO	If YES...
F8a. Tubal ligation (tubes tied)?			what age? _____
F8b. Partner had a vasectomy?			what year? _____

Since your breast cancer diagnosis, have you or your partner used any of the following birth control methods? (Please **circle** the number under your frequency of use for the following methods **since your breast cancer diagnosis.**)

<i>(Circle one number per line)</i>	Never	Rarely	Some of the time	Most of the time
F9a. Birth control pills	0	1	2	3
F9b. What type of birth control pills have you used since your diagnosis? (Mark an "X" in front of all that apply)	<input type="checkbox"/> a. Progestin-only ("mini-pill") <input type="checkbox"/> b. Other Pill type <input type="checkbox"/> c. Don't know			
<i>(Circle one number per line)</i>	Never	Rarely	Some of the time	Most of the time
F10. Contraceptive patch (Ortho Evra)	0	1	2	3
F11. Vaginal contraceptive ring (NuvaRing)	0	1	2	3
F12. Depo Provera	0	1	2	3
F13. Hormonal implant (Norplant or Implanon)	0	1	2	3
F14. "Morning After Pills" (Plan B or Preven)	0	1	2	3
F15. Condom (male or female)	0	1	2	3
F16. Withdrawal/pulling out	0	1	2	3
F17. Rhythm, safe period by calendar, temperature, cervical mucus test	0	1	2	3
F18. Diaphragm, vaginal pouch, cervical cap	0	1	2	3
F19. Foam, jelly or cream, Today sponge	0	1	2	3
F20a. IUD	0	1	2	3
F20b. What type of IUD have you used since your breast cancer diagnosis? (Mark an "X" in front of all that apply)	<input type="checkbox"/> a. Paragard (Copper T) <input type="checkbox"/> b. Mirena <input type="checkbox"/> c. Don't know			
F21. Other Method - <i>Please specify:</i> _____	0	1	2	3

F22. There are a number of reasons why people do not always use birth control. If there are times when you do not use birth control, please select the reasons below that apply to you. (*Mark an "X" in front of all that apply*)

- a. I always use birth control
- b. I have had a tubal ligation ("tubes tied")
- c. My partner has had a vasectomy
- d. I don't think I am able to get pregnant because I am menopausal
- e. I don't think I am able to get pregnant because I was told by a physician that it is unlikely (due to conditions such as blocked fallopian tubes, polycystic ovarian syndrome, low sperm counts, etc.)
- f. If I did get pregnant, I would end the pregnancy
- g. If I did get pregnant, I would have the baby
- h. I don't like using birth control
- i. I have trouble remembering to use birth control
- j. Other - *Please specify:* _____

F23. At any time since your breast cancer diagnosis, have you tried to become pregnant?

- 1. YES
- 2. NO → (Go to Question F26)

F24. At any time since your breast cancer diagnosis, have you tried to become pregnant for at least a year without becoming pregnant?

- 1. YES
- 2. NO → (Go to Question F26)

F25. At any time since your breast cancer diagnosis, did you seek care with a medical professional (doctor or nurse) regarding your difficulty with getting pregnant?

- 1. YES
- 2. NO

F26. At any time since your breast cancer diagnosis, have you been pregnant?

- 1. YES → **F26a.** How many times? _____
- 2. NO → (Go to Page 30, Question F28)

F27. What was the outcome of your pregnancy/pregnancies since your breast cancer diagnosis? (Mark an "X" in front of **one** answer for each pregnancy)

First Pregnancy	<input type="checkbox"/> 1. Currently pregnant <input type="checkbox"/> 2. Live birth <input type="checkbox"/> 3. Pregnancy loss (stillbirth, spontaneous miscarriage) <input type="checkbox"/> 4. Terminated pregnancy (induced abortion) <input type="checkbox"/> 5. Tubal or ectopic pregnancy <input type="checkbox"/> 6. Other – <i>Please specify:</i> _____
Second Pregnancy	<input type="checkbox"/> 1. Currently pregnant <input type="checkbox"/> 2. Live birth <input type="checkbox"/> 3. Pregnancy loss (stillbirth, spontaneous miscarriage) <input type="checkbox"/> 4. Terminated pregnancy (induced abortion) <input type="checkbox"/> 5. Tubal or ectopic pregnancy <input type="checkbox"/> 6. Other – <i>Please specify:</i> _____
Third Pregnancy	<input type="checkbox"/> 1. Currently pregnant <input type="checkbox"/> 2. Live birth <input type="checkbox"/> 3. Pregnancy loss (stillbirth, spontaneous miscarriage) <input type="checkbox"/> 4. Terminated pregnancy (induced abortion) <input type="checkbox"/> 5. Tubal or ectopic pregnancy <input type="checkbox"/> 6. Other – <i>Please specify:</i> _____
Fourth Pregnancy	<input type="checkbox"/> 1. Currently pregnant <input type="checkbox"/> 2. Live birth <input type="checkbox"/> 3. Pregnancy loss (stillbirth, spontaneous miscarriage) <input type="checkbox"/> 4. Terminated pregnancy (induced abortion) <input type="checkbox"/> 5. Tubal or ectopic pregnancy <input type="checkbox"/> 6. Other – <i>Please specify:</i> _____

Now we would like to ask some questions about fertility preservation (this term refers to medical or surgical procedures that help protect your fertility during cancer treatment, including preserving eggs or embryos).

F28. After your breast cancer diagnosis, but before your cancer treatments began, did you ever see a fertility specialist to talk about fertility preservation?

____ 1. YES → (Skip Question F29. Go to Question F30)

____ 2. NO

F29. There are a number of reasons why people do not see a fertility specialist to talk about fertility preservation. If you did not see a fertility specialist, please select the reasons below that apply to you. (Mark an "X" in front of **all that apply**)

____ a. Cost

____ b. Was not referred

____ c. Completed childbearing

____ d. Cancer treatments were too much to deal with

____ e. Not worried about future fertility

____ f. It was not convenient for me

____ g. Other - Please specify: _____

IF YOU ANSWERED QUESTION F29, GO TO PG. 32, END OF SURVEY.

IF YOU SKIPPED QUESTION F29, GO TO QUESTION F30.

F30. Who referred you to the fertility specialist for the fertility preservation consultation? (Mark an "X" in front of **all that apply**)

____ a. Self

____ b. Oncologist

____ c. Gynecologist

____ d. Oncology nursing and social work staff

____ e. Friends or Family

____ f. Online resources such as MyOncoFertility.org or Fertile Hope

____ g. Other - Please specify: _____

Since your breast cancer diagnosis, have you used any of the therapies or medical interventions below to preserve your fertility?

Please mark an "X" in one box for each line, indicating your use of the following therapies or medical interventions <u>since your breast cancer diagnosis</u> .	(1) Before or during treatment	(2) After completing treatment	(3) Did not use this
F31. Embryo banking			
F32. Egg banking			
F33. Ovarian suppression with medication (for example: Lupron)			
F34. Other - <i>Please specify:</i> _____			

F35. Fertility preservation treatments can sometimes be expensive. How did **cost** factor in to your decision about an intervention to improve or preserve fertility? (Mark an "X" in front of only one answer.)

- _____ 1. The cost of fertility preservation interventions was not a major factor in my decision.
- _____ 2. Cost influenced my decision about fertility preservation interventions, but it was not the most important consideration.
- _____ 3. Cost was the most important consideration for my decision about fertility preservation interventions.
- _____ 4. Other - *Please specify:* _____

Please think about the decision you made about the fertility preservation options after talking to the fertility specialist.

Please show how you feel about these statements by circling the number from 1 (strongly agree) to 5 (strongly disagree).	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
F36. It was the right decision.	1	2	3	4	5
F37. I regret the choice I made.	1	2	3	4	5
F38. I would go for the same choice if I had to do it over again.	1	2	3	4	5
F39. The choice did me a lot of harm.	1	2	3	4	5
F40. The decision was a wise one.	1	2	3	4	5

END OF SURVEY

THANK YOU FOR YOUR TIME IN COMPLETING THIS SURVEY.

PLEASE MAIL IT BACK TO US IN THE PRE-PAID ENVELOPE PROVIDED, OR MAIL TO:

**UNC Lineberger Comprehensive Cancer Center - North
Attn: Carolina Breast Cancer Study, Rm. 332
1700 Martin Luther King Jr. Blvd.
Chapel Hill, NC 27514-9862**

You will receive a Thank-You check in the amount of Twenty-Five Dollars (\$25) within three weeks of returning this completed survey.

Questions? Call our toll-free telephone number: 1-866-927-6920.

***THANK YOU FOR ALL YOUR HELP WITH
THE CAROLINA BREAST CANCER STUDY!***