

LTFU

Long-Term Follow-Up Study

St. Jude Children's Research Hospital
 Children's Healthcare of Atlanta/Emory University
 Children's Hospital at Stanford
 Children's Hospital of Colorado
 Children's Hospital of Orange County
 Children's Hospital of Philadelphia
 Children's Hospital of Los Angeles
 Children's Hospital of Pittsburgh
 Children's Hospitals & Clinics of Minnesota,
 Minneapolis and St. Paul
 Children's Medical Center of Dallas
 Children's Memorial Hospital
 Children's National Medical Center
 City of Hope National Medical Center
 Cook Children's Hematology-Oncology Center
 Dana-Farber Cancer Institute/
 Children's Hospital Boston
 Mattel Children's Hospital at UCLA
 Mayo Clinic
 Memorial Sloan-Kettering Cancer Center
 Miller Children's Hospital
 Nationwide Children's Hospital
 Riley Hospital for Children - Indiana University
 Roswell Park Cancer Institute
 Seattle Children's Hospital
 St. Louis Children's Hospital
 Texas Children's Hospital
 Toronto Hospital for Sick Children
 UAB/The Children's Hospital of Alabama
 University of California at San Francisco
 University of Chicago Comer Children's Hospital
 University of Michigan - Mott Children's Hospital
 University of Minnesota
 U.T.M.D. Anderson Cancer Center

Our mailing address is:

Long-Term Follow-Up Study
 St. Jude Children's Research Hospital
 Department of Epidemiology
 Mail Stop 735
 262 Danny Thomas Place
 Memphis, TN 38105-3678

St. Jude toll-free phone number:
 1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

lftu.stjude.org



Dear <Long-Term Follow Up Study Participant's Name>,

We are writing to you with regard to your participation in the Long-Term Follow-Up Study (LTFU). Again, we want to thank you for your continued participation.

We are contacting you to ask you some additional questions regarding your health history, specifically prior to, during and after your diagnosis with breast cancer.

Enclosed with this mailing is a brief questionnaire. We ask that you please complete the questionnaire and return it to us in the included postage-paid envelope within 2 weeks. You can complete the questionnaire online at www.stjude.org/breastcancercalc if you prefer. Your user ID is <randcode> and your password is your date of birth.

Your participation is voluntary. All information collected for this study is confidential and you can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

In order to better understand your experience with breast cancer, we would like to obtain a copy of your medical record. With your permission, we will contact the location or locations where you had your breast cancer diagnosis and treatment and request a copy of your medical record and imaging, as well as any breast biopsy pathology reports prior to your diagnosis. Enclosed is a HIPAA form (medical records release) to allow us to obtain a copy of these records.

We face the daily reality that children are being diagnosed with cancer. With improved treatments, more children are surviving which makes our job all the more important. Such progress is no small part thanks to your help. We would like to thank you for the information which you've already shared and will hopefully share in the near future. While your information will always remain private, your efforts are appreciated by past, present, and future survivors everywhere.

With our sincerest gratitude,

Leslie L. Robison, Ph.D
 Principal Investigator, Long-Term Follow-Up Study
 Director, Epidemiology and Cancer Control
 St. Jude Children's Research Hospital

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
m	m		d	d		y	y	y	y

Please! Do not mark below this line

Survey #142

3730602821

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This form is your permission to use or disclose medical information that we would like you to sign. It will give us permission to obtain copies of portions of your medical record that we may need to review, such as treatment history for your cancer or similar illness, or pathology reports for a subsequent cancer.

**LONG-TERM FOLLOW-UP STUDY
HIPAA¹ AUTHORIZATION TO USE AND DISCLOSE
INDIVIDUAL HEALTH INFORMATION FOR RESEARCH**

- 1. Purpose.** As a research participant and at my request, I authorize Leslie L. Robison, Ph.D. and the researcher's staff to use and disclose my individual health information for the purpose of conducting the research projects entitled Long-Term Follow-Up (LTFU) Study.
 - 2. Individual Health Information to be Used or Disclosed.** My individual health information that may be used or disclosed to conduct this research includes medical records since the diagnosis of a serious illness such as a cardiac condition or a cancer or similar illness.
 - 3. Parties Who May disclose My Individual Health Information.** The researcher and the researcher's staff may obtain my individual health information from hospitals, clinics, and health care providers who have treated me, and health plans that have paid for my care, during this study.
 - 4. Parties Who May Receive or Use My Individual Health Information.** The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Leslie L. Robison, Ph.D., the researcher's staff, Memorial Sloan-Kettering Cancer Center, St. Jude Children's Research Hospital, University of Chicago, the LTFU Biopathology Center (Columbus, OH), the LTFU Molecular Center (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), the LTFU Statistical Center (Seattle, WA), and other LTFU collaborators.
 - 5. Right to Refuse to Sign this Authorization.** I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
 - 6. Right to Revoke.** I can change my mind and withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105 to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for his research study. No further health information about me will be collected by or disclosed to the researcher for this study.
 - 7. Potential for Re-disclosure.** Once my health information is disclosed under this authorization, there is a potential that it may be re-disclosed outside this study and no longer covered by this authorization. However, the research team and the St. Jude Institutional Review Board (the committee that reviews studies to be sure that the rights and safety of study participants are protected) are very careful to protect your privacy and limit the disclosure of identifying information about you.
- 7A. Also,** there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public-health measures.

For participants under the age of majority, this authorization will expire when they reach the age of majority (unless the participant has an appointed legal guardian who has provided authorization). A new authorization will be required when the child reaches the age of majority. For participants over the age of majority, this authorization expires at the end of the study.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I have received a copy of this authorization form.

Printed name of research participant

Date of birth

Sign
Here

Signature of research participant or research
Participant's personal representative

Date

Fill in
Date

Printed name of research participant's personal representative

Description of personal representative's authority to act on behalf of the research participant

¹HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information. The Privacy Rule is 45 CFR Parts 160, 164.

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1. Has your mother, sister (full or half-sister), or daughter ever been diagnosed with breast cancer?

- Yes
- No
- I don't know

For each of your close relatives who have been diagnosed with breast cancer, please tell us their relationship to you, the age at which she was first diagnosed with breast cancer, and the year the diagnosis was made. An example of this would be saying that your mother was diagnosed with breast cancer in 2002 when she was 55 years old.

Relative	Age at diagnosis	Year of diagnosis
Example: <u>Mother</u>	<u>55</u>	<u>2002</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____

2. Have you ever had a menstrual period naturally; that is, without needing hormones or medication?

- Yes → If yes, age at first occurrence:
- No
- Not sure

3. Have you ever given birth?

- Yes
- No

If you have, please list the dates of all the times you have given birth.

	m	m	/	d	d	/	y	y	y	y
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8.	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	/	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	/	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>

The following questions ask you about the time **BEFORE** your breast cancer was diagnosed.

(Clarification: ductal carcinoma in-situ (DCIS) is considered a form of breast cancer)

4. Before your breast cancer was diagnosed, did you have a written summary of the treatment you received for your childhood cancer?

- Yes
- No
- Not sure

5. In the five years before your breast cancer was diagnosed, did you have routine check-ups where a doctor examined you and did tests to see if you had any health problems from your cancer or your cancer treatment?

- Yes, I had a visit less than one year before I was diagnosed with breast cancer
- Yes, I had a visit 1-2 years before I was diagnosed with breast cancer
- Yes, but my last visit was over two years before I was diagnosed with breast cancer
- No
- Not sure

6. Before your breast cancer was diagnosed, when was your last visit at the center where your childhood cancer was treated?

- Less than 1 year before I was diagnosed with breast cancer
- Between 1-2 years before I was diagnosed with breast cancer
- More than 2 years and less than 5 years before I was diagnosed with breast cancer
- 5 or more years before I was diagnosed with breast cancer
- Not sure

7. Before your breast cancer was diagnosed, did a physician or a health provider ever discuss your risk of breast cancer?

- Yes No Not sure

If YES, which health care provider(s) discussed this with you? (Check all that apply)

- Oncologist [pediatric oncologist or medical (adult) oncologist]
- Radiation oncologist
- Primary care physician (family physician or internist)
- Obstetrician/gynecologist
- Nurse practitioner or physician's assistant (PA)
- Other

If Other, please specify:

8. Before your breast cancer was diagnosed, did you perform self-breast exams?

- Yes, every month, always
- Yes, every month, but skipped sometimes
- Yes, every so often
- No

9. Before your breast cancer was diagnosed, did your health care provider perform breast exams?

- Yes, every 6 months, always
- Yes, every 12 months, always
- Yes, sometimes
- No → Skip to Question 10.

If YES, which health care provider performed most of your breast exams?

- Oncologist
- Primary care physician (family physician or internist)
- Obstetrician/Gynecologist
- Nurse practitioner or physician's assistant (PA)
- Other

If Other, please specify:

10. Before your breast cancer was diagnosed, did you have breast augmentation surgery?

- Yes
- No

11. Did you ever have a breast biopsy that was done more than 6 months before your breast cancer diagnosis? Here we are not asking about the biopsy that led to your breast cancer diagnosis, but other breast biopsies that may have happened before you were diagnosed with breast cancer.

- Yes
- No
- I don't know

If YES:

a. Please list the number of breast biopsies you have had:

--	--

b. Please list the institutions where the breast biopsies were done:

- 1. _____
- 2. _____
- 3. _____
- 4. _____

Continue on next page.

The following questions pertain to the diagnosis and imaging of your breast cancer. We are providing you with some definitions in order to make answering the questions easier.

Routine Screening Mammogram - a mammogram that is done for check up purposes only. This type of mammogram is done for a woman that has not had breast symptoms or problems at the time of the routine mammogram. Similarly, a routine screening breast MRI or ultrasound is done for women without any symptoms.

Diagnostic mammogram, ultrasound, or breast MRI - a test that is done to evaluate a problem, such as a pain or lump in the breast

12. At any time before your breast cancer was diagnosed, did a physician ever recommend that you have a routine screening mammogram?

- Yes, I had a routine mammogram
 Yes, he or she did, but I did not have a mammogram

Please give reason:

- No
 I don't remember

13. Before your breast cancer was diagnosed, how often did you have routine mammograms?

- Only had one routine mammogram before my breast cancer was diagnosed
 Every year (annually)
 Once every 1-2 years (not quite annually)
 Every 3-5 years
 Less often than every 5 years
 Never → Skip to Question 14.

At what age did you start having routine screening mammograms:

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14. Before your breast cancer was diagnosed, did you ever have any other breast cancer routine tests, such as a routine screening breast ultrasound or screening breast MRI?

- Yes No

If yes, name of test(s):

15. Before your breast cancer was diagnosed, did you ever take an anti-estrogen medication, for example, Nolvadex (tamoxifen), or Evista (raloxifene)?

- Yes No I am not sure

If yes, name of medication:

Were you on this medication when you were diagnosed with breast cancer?

- Yes No I am not sure

16. Before your breast cancer was diagnosed, did you ever take estrogen hormone replacement therapy, for example, Premarin, Prempro, or Estraderm?

- Yes No I am not sure

If yes, name of medication:

About how long were you on this type of medication?

- Less than one year
 1-2 years
 3-5 years
 6-9 years
 10 or more years

Were you on this medication when you were diagnosed with breast cancer?

- Yes No I am not sure

17. Before your breast cancer was diagnosed, did you ever take a birth control pill, such as Lo-Ovral, or Triphasil?

- Yes
- No
- I am not sure

If yes, name of medication:

About how long were you on this type of medication?

- Less than one year
- 1-2 years
- 3-5 years
- 6-9 years
- 10 or more years

Were you on this medication when you were diagnosed with breast cancer?

- Yes
- No
- I am not sure

The following questions ask you about the time **DURING and AFTER** your breast cancer was diagnosed.

18. What was the date when your breast cancer was first diagnosed?

____ / ____
Month Year

19. At the time your breast cancer was diagnosed, had your menstrual periods stopped permanently?

- Yes, natural menopause (that is, without needing hormones or medication)

If yes, when? ____ Year

- Yes, following removal of my ovaries

If yes, provide date of surgery:

____ / ____
Month Year

- Yes, following radiation or chemotherapy

If yes, when? ____ Year

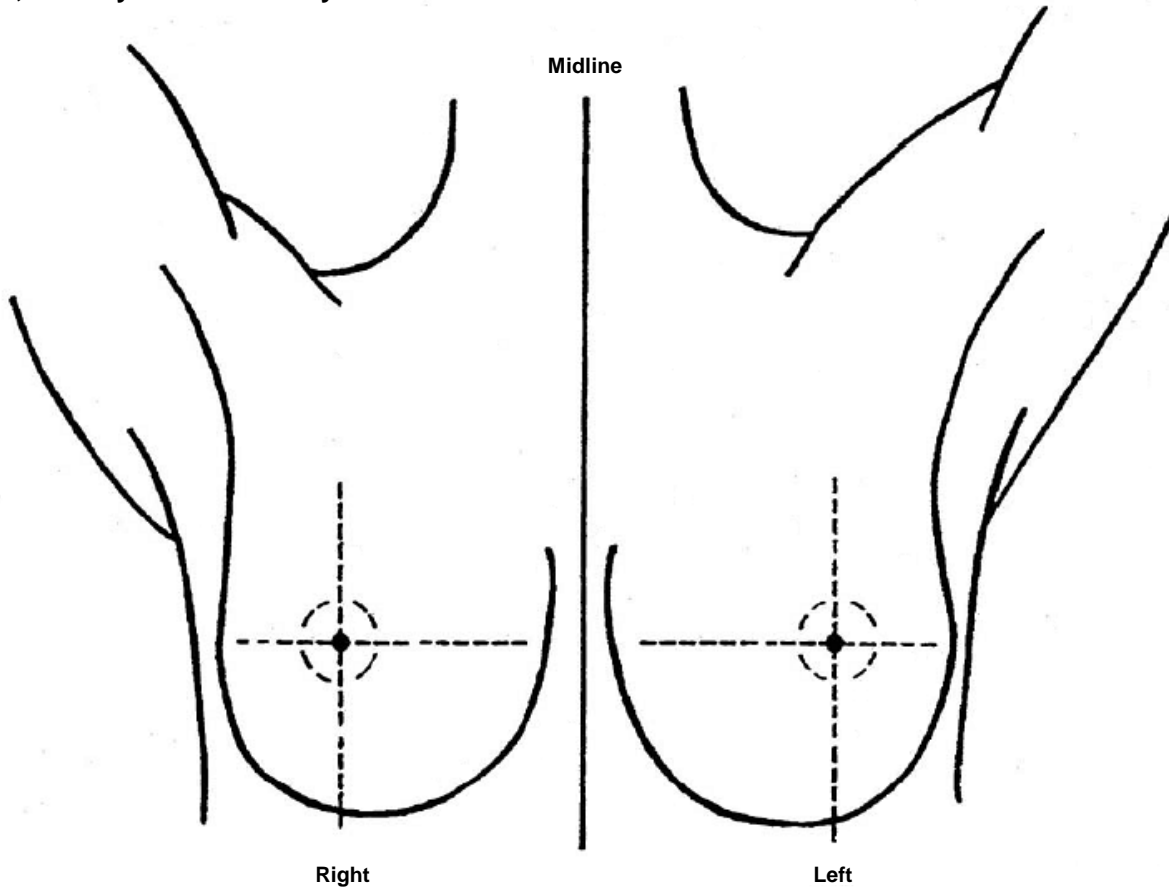
- No
- Not sure

20. How was your breast cancer **first** detected?
(Choose only one)

- You (or your spouse or partner) felt a lump, pain, or a change in your breast that made you go to the doctor
- Your doctor felt a lump at a routine exam
- You had a routine screening mammogram detect an abnormality
- You had a routine screening breast MRI detect an abnormality
- You had a routine screening breast ultrasound detect an abnormality
- Other

If Other, please specify:

21. This question pertains to the location of your breast cancer. We would appreciate it if you would mark this diagram with an "X" at each specific location of a breast cancer(s). We are interested in the most exact location you can provide so please be as specific as possible. If you have had more than one breast cancer, please number the X's (locations) as 1, 2, etc. to denote your first, second, etc. breast cancers. Note the right and left breast labels on the diagram; these labels refer to your right breast and your left breast, not as you would view your breasts in a mirror.



If you are not sure of the exact location and are unable to mark the above diagram, please indicate which breast was affected.

- Left Right Both Not sure

22. Which of the following tests were done around the time of your initial breast cancer diagnosis?

(Check all that apply)

- None
 Mammogram
 Ultrasound of the breast
 MRI of the breast
 I am not sure

23. When your breast cancer was first diagnosed, what type of surgeries did you have?

(Check all that apply)

- Lumpectomy (breast conserving surgery)
 Mastectomy or removal of a breast

↳ **If YES, was one side or both removed?**

- One
 Both

↳ **If Both, why was the second breast removed?**

24. At the time of your breast surgery, was the cancer in your lymph nodes?

- Yes → How many?
- No
- I am not sure

25. Had the cancer spread to anywhere else in the body?

- Yes
- No
- I am not sure

If yes, to where in the body?

26. Do you know the stage of your cancer?

- Yes
- No

If yes, which stage?

27. Did you receive radiation for your breast cancer?

- Yes
- No
- I am not sure

28. Did you receive chemotherapy for your breast cancer?

- Yes
- No
- I am not sure

29. Did you undergo breast reconstruction surgery following your breast cancer diagnosis?

- Yes
- No
- I don't know

If yes, did you have any problems with the reconstruction or the implants?

30. After your breast cancer diagnosis, did you ever take an anti-estrogen medication, for example, Nolvadex (tamoxifen) or aromatase inhibitors such as Femera or Arimidex?

- Yes
- No
- I am not sure

If yes, name of medication:

About how long were you on (or have you been on) this type of medication?

- Less than one year
- 1-2 years
- 3-5 years
- 6-9 years
- 10 or more years

31. Did your breast cancer relapse following treatment?

- Yes
- No

If YES, please give the date of relapse:

____ / ____
(Month) (Year)

What additional treatment did you have following the relapse:

32. Have you ever had genetic testing to see if you have a breast cancer gene or cancer predisposition? These tests include BRCA1 or BRCA2 (breast cancer gene), p53 (test for Li-Fraumeni syndrome) or Fanconi?

- Yes
- No
- I don't know

If YES, and you feel comfortable, please give the name of the test or test(s) and whether the gene was present or not.

Name of test(s)	Result
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____

The next few questions ask your views about your health care. There are no right or wrong answers - please answer how you feel.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Some people are very concerned about their health, while others are not as concerned. How concerned are you about your own health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Some people are very interested in going to the doctor for a general physical exam to check on their health, while others are not as interested. How interested are you about going to a doctor for "routine medical check-ups"?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Some survivors of childhood cancer think that they can develop a health problem from their treatment several years later, while others do not think that they can ever have any more problems related to their previous cancer. How likely do you think it is in the future that you might develop a health problem related to your previous treatment for cancer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. How important do you feel it is for you to have a routine check-up to see if you have any problems caused by the treatment of your cancers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you ever feel uncertain about your future health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you ever worry that your cancers will come back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you ever feel like you are different from others because you had cancers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you ever feel like you want to forget that you had cancer and just be like everyone else?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you ever worry about being called a complainer or a hypochondriac?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you ever worry that a problem with your health will be discovered if you go to a doctor for a routine check-up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you ever worry about getting another cancer in the future (different from your childhood or breast cancer)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continue on back.

Where was your breast cancer diagnosed?

Hospital, Doctor's Name:

Hospital Address, City, State/Province, Zip Code:

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Where was your breast cancer treated?

Hospital, Doctor's Name:

Hospital Address, City, State/Province, Zip Code:

--	--

Hospital 2:

--	--

Hospital 3:

--	--

Hospital 4:

--	--

If you were treated at more hospitals, please list the information on a separate sheet of paper and return with this survey.

Thank you Is there anything else that you would like to share?

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Please! Do not mark below this line

LTFU

Long-Term Follow-Up Study

St. Jude Children's Research Hospital
 Children's Healthcare of Atlanta/Emory University
 Children's Hospital at Stanford
 Children's Hospital of Colorado
 Children's Hospital of Orange County
 Children's Hospital of Philadelphia
 Children's Hospital of Los Angeles
 Children's Hospital of Pittsburgh
 Children's Hospitals & Clinics of Minnesota,
 Minneapolis and St. Paul
 Children's Medical Center of Dallas
 Children's Memorial Hospital
 Children's National Medical Center
 City of Hope National Medical Center
 Cook Children's Hematology-Oncology Center
 Dana-Farber Cancer Institute/
 Children's Hospital Boston
 Mattel Children's Hospital at UCLA
 Mayo Clinic
 Memorial Sloan-Kettering Cancer Center
 Miller Children's Hospital
 Nationwide Children's Hospital
 Riley Hospital for Children - Indiana University
 Roswell Park Cancer Institute
 Seattle Children's Hospital
 St. Louis Children's Hospital
 Texas Children's Hospital
 Toronto Hospital for Sick Children
 UAB/The Children's Hospital of Alabama
 University of California at San Francisco
 University of Chicago Comer Children's Hospital
 University of Michigan - Mott Children's Hospital
 University of Minnesota
 U.T.M.D. Anderson Cancer Center



Dear <Long-Term Follow Up Study Participant's Proxy's Name>,

We are writing to you with regard to <participant's name>'s participation in the Long-Term Follow-Up Study (LTFU). We share in your loss of <participant's name>. She, like so many others, was valiant in her fight against cancer. Our goal is to improve the treatment of childhood cancer and maximize the health of cancer survivors. To accomplish this goal, in 1994 we established the LTFU Study with 26 participating cancer centers from around the United States and Canada.

We are contacting you to ask you some additional questions regarding <participant's name>'s health history, specifically prior to, during and after her diagnosis with breast cancer.

Enclosed with this mailing is a brief questionnaire. We ask that you please complete the questionnaire and return it to us in the included postage-paid envelope within 2 weeks. If you prefer, you can complete the questionnaire online at www.stjude.org/breastcancercalc. Your user ID is <randcode> and your password is <participant's name>'s date of birth. If you can't recall her date of birth please call us at the toll-free number below.

Your participation is voluntary. All information collected for this study is confidential and you can be assured that we will respect <participant's name>'s and your privacy at all times. Her name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

We face the daily reality that children are being diagnosed with cancer. With improved treatments, more children are surviving which makes our job all the more important. Such progress is in no small part thanks to your help. We would like to thank you, on <participant's name>'s behalf, for the information which you've already shared and will hopefully share in the near future. While your and <participant's name>'s information will always remain private, your efforts are appreciated by past, present, and future survivors everywhere.

With our sincerest gratitude,

Leslie L. Robison, Ph.D
 Principal Investigator, Long-Term Follow-Up Study
 Director, Epidemiology and Cancer Control
 St. Jude Children's Research Hospital

Our mailing address is:
 Long-Term Follow-Up Study
 St. Jude Children's Research Hospital
 Department of Epidemiology
 Mail Stop 735
 262 Danny Thomas Place
 Memphis, TN 38105-3678

St. Jude toll-free phone number:
 1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

ltfu.stjude.org

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
m	m		d	d		y	y	y	y

Please! Do not mark below this line

Survey #143

3693403367

Person completing this questionnaire is:

(Print your full name)

Please specify your relationship to <participant>.

1. Has <participant's name>'s mother, sister (full or half-sister), or daughter ever been diagnosed with breast cancer?

Yes No I don't know

For each of <participant's name>'s close relatives who have been diagnosed with breast cancer, please tell us their relationship to her, the age at which she was first diagnosed with breast cancer, and the year the diagnosis was made. An example of this would be saying that <participant's name>'s mother was diagnosed with breast cancer in 2002 when she was 55 years old.

Relative	Age at diagnosis	Year of diagnosis
Example: Mother	55	2002
_____	_____	_____
_____	_____	_____
_____	_____	_____

2. Did <participant's name> ever have a menstrual period naturally; that is, without needing hormones or medication?

Yes → If yes, age at first occurrence:
 No
 Not sure

3. Had she ever given birth?

Yes No

If she had, please list the dates of all the times she gave birth.

	m	m	/	d	d	/	y	y	y	y
1.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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3.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
5.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
8.	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

The following questions ask you about the time **BEFORE** <participant's name>'s breast cancer was diagnosed.

(Clarification: ductal carcinoma in-situ (DCIS) is considered a form of breast cancer)

4. Before her breast cancer was diagnosed, did she have a written summary of the treatment she received for her childhood cancer?

Yes
 No
 Not sure

5. In the five years before her breast cancer was diagnosed, did she have routine check-ups where a doctor examined her and did tests to see if she had any health problems from her childhood cancer or her childhood cancer treatment?

Yes, she had a visit less than one year before she was diagnosed with breast cancer
 Yes, she had a visit 1-2 years before she was diagnosed with breast cancer
 Yes, but her last visit was over two years before she was diagnosed with breast cancer
 No
 Not sure

6. Before her breast cancer was diagnosed, when was her last visit at the center where her childhood cancer was treated?

Less than 1 year before she was diagnosed with breast cancer
 Between 1-2 years before she was diagnosed with breast cancer
 More than 2 years and less than 5 years before she was diagnosed with breast cancer
 5 or more years before she was diagnosed with breast cancer
 Not sure

7. Before her breast cancer was diagnosed, did a physician or a health provider ever discuss her risk of breast cancer with her?

- Yes No Not sure

If YES, which health care provider(s) discussed this with her? (Check all that apply)

- Oncologist [pediatric oncologist or medical (adult) oncologist]
- Radiation oncologist
- Primary care physician (family physician or internist)
- Obstetrician/gynecologist
- Nurse practitioner or physician's assistant (PA)
- Other

If Other, please specify:

8. Before her breast cancer was diagnosed, did she perform self-breast exams?

- Yes, every month, always
- Yes, every month, but skipped sometimes
- Yes, every so often
- Yes, but I don't know how often
- No
- I don't know

9. Before her breast cancer was diagnosed, did her health care provider perform breast exams?

- Yes, every 6 months, always
- Yes, every 12 months, always
- Yes, sometimes
- Yes, but I don't know how often
- No
- I don't know

If YES, which health care provider performed most of her breast exams?

- Oncologist
- Primary care physician (family physician or internist)
- Obstetrician/Gynecologist
- Nurse practitioner or physician's assistant (PA)
- Other

If Other, please specify:

- I don't know

10. Before her breast cancer was diagnosed, did she have breast augmentation surgery?

- Yes
- No
- I am not sure

11. Did she ever have a breast biopsy that was done more than 6 months before her breast cancer diagnosis? Here we are not asking about the biopsy that led to her breast cancer diagnosis, but other breast biopsies that may have happened before she was diagnosed with breast cancer.

- Yes
- No
- I don't know

If YES:

a. Please list the number of breast biopsies she had:

--	--

b. Please list the institutions where the breast biopsies were done:

1. _____
2. _____
3. _____
4. _____

Continue on next page.

The following questions pertain to the diagnosis and imaging of <participant's name>'s breast cancer. We are providing you with some definitions in order to make answering the questions easier.

Routine Screening Mammogram - a mammogram that is done for check up purposes only. This type of mammogram is done for a woman that has not had breast symptoms or problems at the time of the routine mammogram. Similarly, a routine screening breast MRI or ultrasound is done for women without any symptoms.

Diagnostic mammogram, ultrasound, or breast MRI - a test that is done to evaluate a problem, such as a pain or lump in the breast

12. At any time before her breast cancer was diagnosed, did a physician ever recommend that she have a routine screening mammogram?

- Yes, she had a routine mammogram
- Yes, he or she did, but she did not have a mammogram

Please give reason:

- No
- I am not sure

13. Before her breast cancer was diagnosed, how often did she have routine mammograms?

- Only had one routine mammogram before her breast cancer was diagnosed
- Every year (annually)
- Once every 1-2 years (not quite annually)
- Every 3-5 years
- Less often than every 5 years
- Never → Skip to Question 14.
- I don't know

At what age did she start having routine screening mammograms:

--	--

14. Before her breast cancer was diagnosed, did she ever have any other breast cancer routine tests, such as a routine screening breast ultrasound or screening breast MRI?

- Yes
- No
- I don't know

If yes, name of test(s):

15. Before her breast cancer was diagnosed, did she ever take an anti-estrogen medication, for example, Nolvadex (tamoxifen), or Evista (raloxifene)?

- Yes
- No
- I am not sure

If yes, name of medication:

Was she on this medication when she was diagnosed with breast cancer?

- Yes
- No
- I am not sure

16. Before her breast cancer was diagnosed, did she ever take estrogen hormone replacement therapy, for example, Premarin, Prempro, or Estraderm?

- Yes
- No
- I am not sure

If yes, name of medication:

About how long was she on this type of medication?

- Less than one year 6-9 years
- 1-2 years 10 or more years
- 3-5 years I am not sure

Was she on this medication when she was diagnosed with breast cancer?

- Yes
- No
- I am not sure

17. Before her breast cancer was diagnosed, did she ever take a birth control pill, such as Lo-Ovral, or Triphasil?

- Yes
- No
- I am not sure

If yes, name of medication:

About how long was she on this type of medication?

- Less than one year 6-9 years
- 1-2 years 10 or more years
- 3-5 years I am not sure

Was she on this medication when she was diagnosed with breast cancer?

- Yes
- No
- I don't know

The following questions ask you about the time **DURING** and **AFTER** <participant's name>'s breast cancer was diagnosed.

18. What was the date when her breast cancer was first diagnosed?

____ / ____ / ____
Month Year

- I am not sure

19. At the time her breast cancer was diagnosed, had her menstrual periods stopped permanently?

- Yes, natural menopause (that is, without needing hormones or medication)

If yes, when? ____ Year

- Yes, following removal of her ovaries

If yes, provide date of surgery:

____ / ____ / ____
Month Year

- Yes, following radiation or chemotherapy

If yes, when? ____ Year

- No
- Not sure

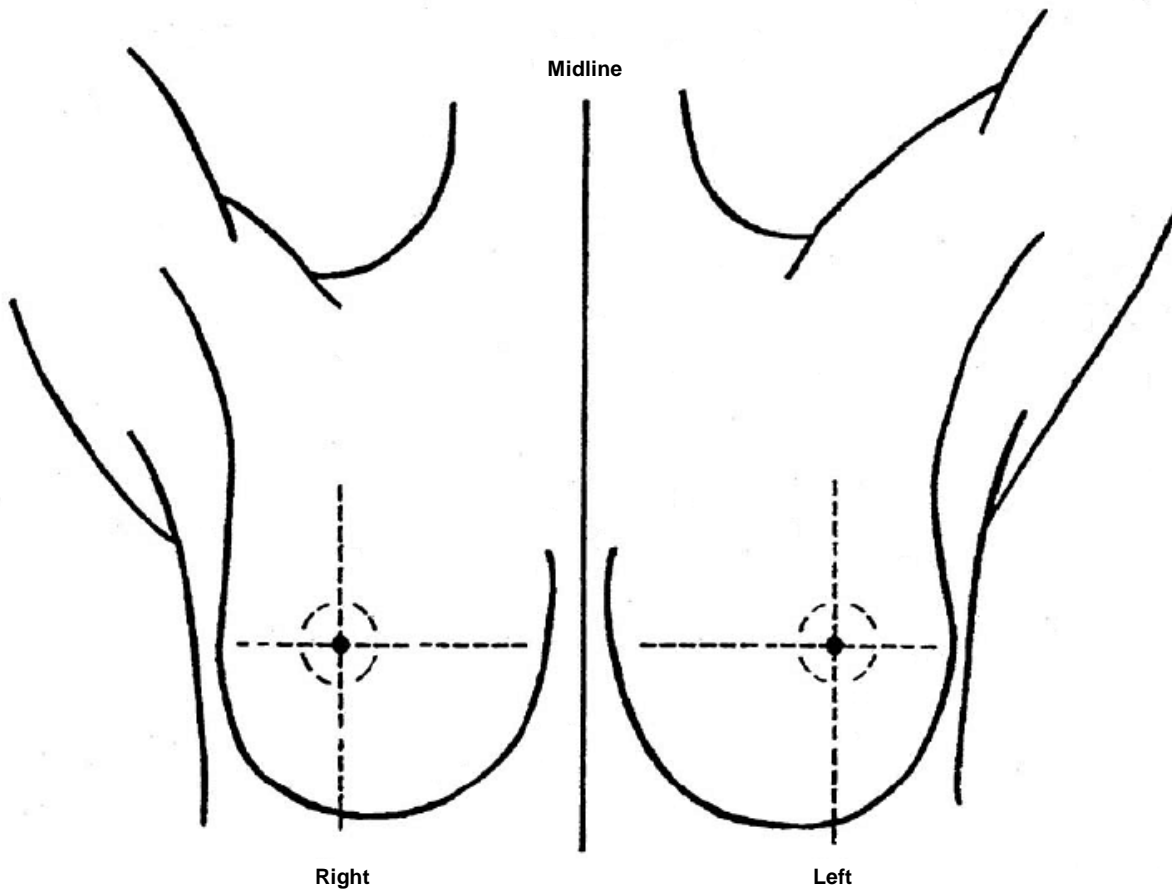
20. How was her breast cancer **first** detected? *(Choose only one)*

- She (or her spouse or partner) felt a lump, pain, or a change in her breast that made her go to the doctor
- Her doctor felt a lump at a routine exam
- She had a routine screening mammogram detect an abnormality
- She had a routine screening breast MRI detect an abnormality
- She had a routine screening breast ultrasound detect an abnormality
- Other

If Other, please specify:

- I am not sure

21. We are interested in knowing the location of <participant's name>'s breast cancer. We would like to know the most exact location you can provide, so please be as specific as possible. If she had more than one breast cancer, please number the X's (locations) as 1, 2, etc. to denote her first, second, etc. breast cancer.



If you are not sure of the exact location and are unable to mark the above diagram, please indicate which breast was affected.

- Left Right Both Not sure

22. Which of the following tests were done around the time of her initial breast cancer diagnosis?
(Check all that apply)

- None
 Mammogram
 Ultrasound of the breast
 MRI of the breast
 I am not sure

23. When her breast cancer was first diagnosed, what type of surgeries did she have?
(Check all that apply)

- Lumpectomy (breast conserving surgery)
 Mastectomy or removal of a breast
 ↳ *If YES, was one side or both removed?*
 One
 Both

↳ *If Both, why was the second breast removed?*

- I am not sure

24. At the time of her breast surgery, was the cancer in her lymph nodes?

- Yes → How many?
- No
- I am not sure

25. Had the cancer spread to anywhere else in the body?

- Yes
- No
- I am not sure

If yes, to where in the body?

26. Do you know the stage of her cancer?

- Yes
- No

If yes, which stage?

27. Did she receive radiation for her breast cancer?

- Yes
- No
- I am not sure

28. Did she receive chemotherapy for her breast cancer?

- Yes
- No
- I am not sure

29. Did she undergo breast reconstruction surgery following her breast cancer diagnosis?

- Yes
- No
- I don't know

If yes, did she have any problems with the reconstruction or the implants?

30. After her breast cancer diagnosis, did she ever take an anti-estrogen medication, for example, Nolvadex (tamoxifen) or aromatase inhibitors such as Femera or Arimidex?

- Yes
- No
- I am not sure

If yes, name of medication:

About how long was she on this type of medication?

- Less than one year
- 1-2 years
- 3-5 years
- 6-9 years
- 10 or more years
- I am not sure

31. Did her breast cancer relapse following treatment?

- Yes
- No
- I don't know

If YES, please give the date of relapse:

____ / ____
 Month Year

What additional treatment did she have following the relapse:

32. Did she ever have genetic testing to see if she had a breast cancer gene or cancer predisposition? These tests include BRCA1 or BRCA2 (breast cancer gene), p53 (test for Li-Fraumeni syndrome) or Fanconi?

- Yes
- No
- I don't know

If YES, and you feel comfortable, please give the name of the test or test(s) and whether the gene was present or not.

Name of test(s)	Result
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____

Where was her breast cancer diagnosed?	Hospital, Doctor's Name:	Hospital Address, City, State/Province, Zip Code:

Where was her breast cancer treated?	Hospital, Doctor's Name:	Hospital Address, City, State/Province, Zip Code:
Hospital 2:		

If she was treated at more hospitals, please list the information on a separate sheet of paper and return with this survey.

Thank you Is there anything else that you would like to share?

LTFU

Long-Term Follow-Up Study



- St. Jude Children's Research Hospital
- Children's Healthcare of Atlanta/Emory University
- Children's Hospital at Stanford
- Children's Hospital of Colorado
- Children's Hospital of Orange County
- Children's Hospital of Philadelphia
- Children's Hospital of Los Angeles
- Children's Hospital of Pittsburgh
- Children's Hospitals & Clinics of Minnesota,
Minneapolis and St. Paul
- Children's Medical Center of Dallas
- Children's Memorial Hospital
- Children's National Medical Center
- City of Hope National Medical Center
- Cook Children's Hematology-Oncology Center
- Dana-Farber Cancer Institute/
Children's Hospital Boston
- Mattel Children's Hospital at UCLA
- Mayo Clinic
- Memorial Sloan-Kettering Cancer Center
- Miller Children's Hospital
- Nationwide Children's Hospital
- Riley Hospital for Children - Indiana University
- Roswell Park Cancer Institute
- Seattle Children's Hospital
- St. Louis Children's Hospital
- Texas Children's Hospital
- Toronto Hospital for Sick Children
- UAB/The Children's Hospital of Alabama
- University of California at San Francisco
- University of Chicago Comer Children's Hospital
- University of Michigan - Mott Children's Hospital
- University of Minnesota
- U.T.M.D. Anderson Cancer Center

Dear <Long-Term Follow Up Study Participant's Name>,

We are writing to you with regard to your participation in the Long-Term Follow-Up Study (LTFU). Again, we want to thank you for your continued participation.

One of the cancer treatments that you received was radiation to the chest area. Radiation to the chest area can increase a woman's risk of developing breast cancer. We are studying factors that may influence this risk of breast cancer. While you have not had breast cancer as far as we are aware, your health history can be very informative in the care of countless other women treated with chest radiation, both during the time period you were treated as well as those who are treated today.

Enclosed with this mailing is a brief questionnaire. We ask that you please complete the questionnaire and return it to us in the included postage-paid envelope within 2 weeks. If you prefer, you can complete the questionnaire online at www.stjude.org/breastcancercalc. Your user ID is <randcode> and your password is your date of birth.

One of the questions we ask is whether you have ever had a breast biopsy. If you did, we would like to obtain a copy of the pathology report. With your permission, we will contact the location(s) where you had a biopsy and request a copy of the result. Enclosed is a HIPAA form (medical records release) to allow us to obtain a copy of the pathology report(s) for any of the breast biopsies that you may have had. If you have had a breast biopsy, please fill out the form, sign it, and include it in the envelope with your completed questionnaire. If you did not have a breast biopsy, this form does not need to be completed or signed.

Your participation is voluntary. All information collected for this study is confidential and you can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

We face the daily reality that children are being diagnosed with cancer. With improved treatments, more children are surviving which makes our job all the more important. Such progress is in no small part thanks to your help. We would like to thank you for the information which you've already shared and will hopefully share in the near future. While your information will always remain private, your efforts are appreciated by past, present, and future survivors everywhere.

With our sincerest gratitude,

Leslie L. Robison, Ph.D
Principal Investigator, Long-Term Follow-Up Study
Director, Epidemiology and Cancer Control
St. Jude Children's Research Hospital

Our mailing address is:
Long-Term Follow-Up Study
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

St. Jude toll-free phone number:
1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

ltfu.stjude.org

Today's date: / /
m m d d y y y y

Please! Do not mark below this line

Survey #144

1573033305

This form is your permission to use or disclose medical information that we would like you to sign. It will give us permission to obtain copies of portions of your medical record that we may need to review, such as treatment history for your cancer or similar illness, or pathology reports for a subsequent cancer.

**LONG-TERM FOLLOW-UP STUDY
HIPAA¹ AUTHORIZATION TO USE AND DISCLOSE
INDIVIDUAL HEALTH INFORMATION FOR RESEARCH**

- 1. Purpose.** As a research participant and at my request, I authorize Leslie L. Robison, Ph.D. and the researcher's staff to use and disclose my individual health information for the purpose of conducting the research projects entitled Long-Term Follow-Up (LTFU) Study.
 - 2. Individual Health Information to be Used or Disclosed.** My individual health information that may be used or disclosed to conduct this research includes medical records since the diagnosis of a serious illness such as a cardiac condition or a cancer or similar illness.
 - 3. Parties Who May disclose My Individual Health Information.** The researcher and the researcher's staff may obtain my individual health information from hospitals, clinics, and health care providers who have treated me, and health plans that have paid for my care, during this study.
 - 4. Parties Who May Receive or Use My Individual Health Information.** The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Leslie L. Robison, Ph.D., the researcher's staff, Memorial Sloan-Kettering Cancer Center, St. Jude Children's Research Hospital, University of Chicago, the LTFU Biopathology Center (Columbus, OH), the LTFU Molecular Center (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), the LTFU Statistical Center (Seattle, WA), and other LTFU collaborators.
 - 5. Right to Refuse to Sign this Authorization.** I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
 - 6. Right to Revoke.** I can change my mind and withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105 to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for his research study. No further health information about me will be collected by or disclosed to the researcher for this study.
 - 7. Potential for Re-disclosure.** Once my health information is disclosed under this authorization, there is a potential that it may be re-disclosed outside this study and no longer covered by this authorization. However, the research team and the St. Jude Institutional Review Board (the committee that reviews studies to be sure that the rights and safety of study participants are protected) are very careful to protect your privacy and limit the disclosure of identifying information about you.
- 7A. Also,** there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public-health measures.

For participants under the age of majority, this authorization will expire when they reach the age of majority (unless the participant has an appointed legal guardian who has provided authorization). A new authorization will be required when the child reaches the age of majority. For participants over the age of majority, this authorization expires at the end of the study.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I have received a copy of this authorization form.

Printed name of research participant

Date of birth

Sign Here

Signature of research participant or research
Participant's personal representative

Date

Fill in Date

Printed name of research participant's personal representative

Description of personal representative's authority to act on behalf of the research participant

¹HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information. The Privacy Rule is 45 CFR Parts 160, 164.

Please! Do not mark below this line

1. Have you ever been diagnosed with breast cancer?

(Mark one response)

- Yes
- No
- Unsure

If YES, please indicate the month and year you were diagnosed and the institution where the diagnosis was made:

/
 Month Year

Institution: _____

2. Has your mother, sister (full or half-sister), or daughter ever been diagnosed with breast cancer?

- Yes
- No
- Unsure

For each of your close relatives who have been diagnosed with breast cancer, please tell us their relationship to you, the age at which she was first diagnosed with breast cancer, and the year the diagnosis was made. An example of this would be saying that your mother was diagnosed with breast cancer in 2002 when she was 55 years old.

Relative	Age at diagnosis	Year of diagnosis
Example: <i>Mother</i>	<i>55</i>	<i>2002</i>
_____	_____	_____
_____	_____	_____
_____	_____	_____

3. Have you ever had a menstrual period naturally; that is, without needing hormones or medication?

- Yes → If yes, age at first occurrence:
- No
- Not sure

4. Have you ever had a breast biopsy?

- Yes
- No
- Unsure

If YES:

a. Please list the number of breast biopsies you have had:

b. Please list the institutions where the breast biopsies were done:

1. _____
2. _____
3. _____
4. _____

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LTFU

Long-Term Follow-Up Study

St. Jude Children's Research Hospital
 Children's Healthcare of Atlanta/Emory University
 Children's Hospital at Stanford
 Children's Hospital of Colorado
 Children's Hospital of Orange County
 Children's Hospital of Philadelphia
 Children's Hospital of Los Angeles
 Children's Hospital of Pittsburgh
 Children's Hospitals & Clinics of Minnesota,
 Minneapolis and St. Paul
 Children's Medical Center of Dallas
 Children's Memorial Hospital
 Children's National Medical Center
 City of Hope National Medical Center
 Cook Children's Hematology-Oncology Center
 Dana-Farber Cancer Institute/
 Children's Hospital Boston
 Mattel Children's Hospital at UCLA
 Mayo Clinic
 Memorial Sloan-Kettering Cancer Center
 Miller Children's Hospital
 Nationwide Children's Hospital
 Riley Hospital for Children - Indiana University
 Roswell Park Cancer Institute
 Seattle Children's Hospital
 St. Louis Children's Hospital
 Texas Children's Hospital
 Toronto Hospital for Sick Children
 UAB/The Children's Hospital of Alabama
 University of California at San Francisco
 University of Chicago Comer Children's Hospital
 University of Michigan - Mott Children's Hospital
 University of Minnesota
 U.T.M.D. Anderson Cancer Center



Dear <Long-Term Follow Up Study Participant's Proxy's Name>,

We are writing to you with regard to <participant's name>'s participation in the Long-Term Follow-Up Study (LTFU). We share in your loss of <participant's name>. She, like so many others, was valiant in her fight against cancer. Our goal is to improve the treatment of childhood cancer and maximize the health of cancer survivors. To accomplish this goal, in 1994 we established the LTFU Study with 26 participating cancer centers from around the United States and Canada.

One of the cancer treatments that <participant's name> received was radiation to the chest area. Radiation to the chest area can increase a woman's risk of developing breast cancer. We are studying factors that may influence this risk of breast cancer. While <participant's name> did not have breast cancer, her health history can be very informative in the care of countless other women treated with chest radiation, both during the time period <participant's name> was treated as well as those who are treated today.

We would like to ask you 4 brief questions about <participant's name>'s health history. Your participation is voluntary. All information collected for this study is confidential and you can be assured that we will respect <participant's name>'s and your privacy at all times. Her name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Please complete the enclosed survey and mail it back to us within 2 weeks in the pre-addressed, pre-stamped envelope. If you prefer, you can complete the questionnaire online at www.stjude.org/breastcancercalc. Your user ID is <randcode> and your password is <participant's name>'s date of birth. If you can't recall her date of birth please call us at the toll-free number below.

We face the daily reality that children are being diagnosed with cancer. With improved treatments, more children are surviving which makes our job all the more important. Such progress is in no small part thanks to your help. We would like to thank you, on <participant's name>'s behalf, for the information which you've already shared and will hopefully share in the near future. While your and <participant's name>'s information will always remain private, your efforts are appreciated by past, present, and future survivors everywhere.

With our sincerest gratitude,

Leslie L. Robison, Ph.D
 Principal Investigator, Long-Term Follow-Up Study
 Director, Epidemiology and Cancer Control
 St. Jude Children's Research Hospital

Our mailing address is:
 Long-Term Follow-Up Study
 St. Jude Children's Research Hospital
 Department of Epidemiology
 Mail Stop 735
 262 Danny Thomas Place
 Memphis, TN 38105-3678

St. Jude toll-free phone number:
 1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

ltfu.stjude.org

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
m	m		d	d		y	y	y	y

Please! Do not mark below this line

Survey #145

8590100531

Person completing this questionnaire is:

(Print your full name)

Please specify your relationship to <participant's name>.

1. Was <participant's name> ever diagnosed with breast cancer? (Mark one response)

- Yes
- No
- Unsure

If YES, please indicate the month and year she was diagnosed and the institution where this diagnosis was made:

Month	/									Year

Institution: _____

2. Has <participant's name>'s mother, sister (full or half-sister), or daughter ever been diagnosed with breast cancer?

- Yes
- No
- Unsure

For each of <participant's name>'s close relatives who have been diagnosed with breast cancer, please tell us their relationship to her, the age at which she was first diagnosed with breast cancer, and the year the diagnosis was made. An example of this would be saying that <participant's name>'s mother was diagnosed with breast cancer in 2002 when she was 55 years old.

	<u>Relative</u>	<u>Age at diagnosis</u>	<u>Year of diagnosis</u>
Example: Mother	55	2002	

3. Did <participant's name> ever have a menstrual period naturally; that is, without needing hormones or medication?

- Yes → If yes, age at first occurrence:

--	--
- No
- Not sure

4. Did <participant's name> ever have a breast biopsy?

- Yes
- No
- Unsure

If YES:

a. Please list the number of breast biopsies she had:

--	--

b. Please list the institutions where the breast biopsies were done:

1. _____
2. _____
3. _____
4. _____