

<Participant Research ID>

Dear <NAME>

Thank you for your continued participation with the New York site of the Breast Cancer Family Registry. Many important findings have already arisen from the contributions that you and 30,000 other women and their families have made over the last 15 or more years. To date over 300 scientific papers have been published.

We have now been funded by the National Cancer Institute (USA) to conduct an important new international study using the Breast Cancer Family Registry. The aim of this study is to use all of the new findings that are emerging on genes and environmental risk factors so that we can more accurately predict breast cancer risk for all women. This new study will also help answer important questions for clinical care of women who have a family history of breast cancer, whether or not they are found to have a mutation in one of the known breast cancer predisposition genes.

To conduct this study, we would like to update some of the information that you gave us previously. We have done our best to make this a short survey because we know how valuable your time is. The questionnaire has only 10 questions and will take about 10 minutes or less to complete.

We have asked you some of these questions in the past, but would like you to answer these questions with respect to any changes that have happened since you last completed an interview or questionnaire for us. For ease of administration we are giving the same questionnaire to all participants, so please excuse any questions that do not directly apply to you.

The last time you completed a research questionnaire for our study was: <DATE>

If you are unsure about the answer to any of the questions, it would still help us greatly if you give us your best estimate. If you have any questions or would like assistance in completing this questionnaire, please call us at **1-855-34-FAMILY** or **212-304-6433** or e-mail us at **info@metronyregistry.org**.

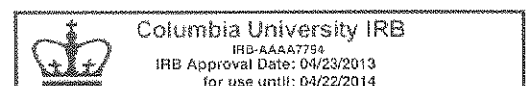
Please fill out the attached questionnaire and return it to us in the stamped envelope provided.

We may want to speak with you about some of your answers to clarify or get more details. We have therefore asked you to provide your telephone number(s) and time(s) that might suit you should we need to contact you.

Thank you again for your generous contributions to breast cancer research.

Sincerely,

Dr. Mary Beth Terry
Principal Investigator



- a. If YES: In which breast did you have the recurrence?
 Left Right Both
- b. If YES: If the recurrence was not in your breasts, where was it?
 Site of recurrence _____
- c. If YES: How old were you when this recurrence was diagnosed? _____ years

8. Since <DATE>, have you had a diagnosis of any other type of cancer besides breast cancer, including sarcoma, leukemia, lymphoma, or any other malignant tumor (do not include non-melanoma skin cancer)?

- No Yes Don't Know

a. If YES: Where in the body did this cancer begin? _____

b. If YES: How old were you when this cancer was diagnosed? _____ years

QUESTIONS 9 and 10 ASK ABOUT YOUR BLOOD RELATIVES

9. Since <DATE>, have any of your blood relatives developed any cancers or tumors (do not include non-melanoma skin cancer)? We are asking about your parents, grandparents, and any children, sisters, brothers, grandchildren, aunts, uncles, nieces, nephews, and any other more distant blood relatives you may have (for example, cousins and their children).

- No Yes Don't Know

If YES:

Name	Relationship to you (for example mother's father, cousin on father's side)	Type of Cancer	Date of diagnosis Month/Year

10. Since <DATE>, have any of your blood relatives died? We are asking about your parents, grandparents, and any children, sisters, brothers, grandchildren, aunts, uncles, nieces, nephews, and any other more distant blood relatives you may have (for example, cousins and their children).

- No Yes Don't Know

If YES:

Name	Relationship to you (for example mother's father, cousin on father's side)	Cause of death	Date of death Month/Year

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Thank you for taking the time to complete this questionnaire. We might need to call you with some follow-up questions.

In order to assist us with any additional contacts, please kindly provide the following information for our records. This information will be stored separately from your questionnaire data. Questionnaire data will be stored and used with only a study identification number.

What is your full name (first, middle, last)? _____

Former last names (if any) _____

We may want to speak with you about some of your answers to clarify or get more details.

Please provide your current contact information and indicate the best time to contact you and your preferred means of contact.

Home phone: _____ Best time/day _____ Preference []

Cell phone: _____ Best time/day _____ Preference []

Work phone: _____ Best time/day _____ Preference []

E-mail: _____ Preference []

If possible, please provide the last four digits of your social security number. This will help us for future contacts over time.

Last 4 digits of Social Security Number : _____

If you have any comments or additional information (such as other relatives diagnosed with cancer) you would like to give us, please feel free to write them below, and if needed, on the back of this page:
