*Revised 7-12-2016*

BREAST CANCER FAMILY REGISTRY

FOLLOW-UP QUESTIONNAIRE

Thank you for taking the time to complete this new survey. Your voluntary participation in this research is greatly appreciated. The information you provide will be kept private and confidential. Note that this particular survey is a newer survey that is quite different from the questionnaires that you have filled out in the past for the Family Registry. It has 3 main sections ***(Thoughts about Cancer and Genetics, Medical History and Lifestyle, and Health Information Updates)*** and it will take about 45 minutes or less to complete.

We would like to introduce some very new and important fields of interest (such as your thoughts about cancer, risk of breast cancer and personal genetics) to gather more information about your thoughts and opinions about these topics. We would also like to update some of the information that you have previously provided to us. We may have asked you some of these questions in the past, but would like you to answer them with respect to any changes that may have occurred since you last completed an interview with us. For ease of administration we are giving the same survey to all participants, so please excuse any questions that may not directly apply to you.

**If you are unsure about the answer to any of the questions, please give us your best estimate. If you have any questions or would like assistance in completing this survey, please do not hesitate to call us at <site phone number> or e-mail us at <site email>.**

After we receive your completed survey, we will review it and if we have questions, we may call you back for clarification.

Again, we appreciate your participation and thank you very much for your time.

**Please proceed to the next page to see a summary of the 3 main sections of the survey**

***Please answer all questions whether or not you have been diagnosed with breast cancer.***

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***Thank you so very much for your ongoing support of breast cancer research! Please answer all questions whether or not you have been diagnosed with breast cancer.***

**SECTION A: YOU AND YOUR THOUGHTS ABOUT CANCER AND GENETICS**

**A1. Background Information**

*To begin with, we would like to confirm a few details for our records.*

1. What is your full name? \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

*First Name Middle Name Last Name*

# 2. What is your date of birth? \_\_\_\_/\_\_\_\_\_/\_\_\_\_\_\_\_

*Month Day Year*

# 3. What is today’s date? \_\_\_\_/\_\_\_\_\_/\_\_\_\_\_\_ *Month Day Year*

*We want to be sure we have the most current contact information for you. Please update your contact information below for our records. This information will be stored separately from your survey data.*

E-mail: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Home phone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ Cell phone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Work phone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Mailing Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_­­\_\_\_\_\_\_\_\_\_\_\_

Street City State Zip

*For future studies, please check if you would prefer to complete surveys:*

on paper online by phone

**A2. Your Psychosocial Well-being: How Are You Feeling?**

*Please choose an answer that comes closest to how you have been feeling* ***in the past week****. Don’t take too long to provide your answer: your immediate reaction to each statement will probably be more accurate than a long thought out response.**For each statement, please check one answer. If you don’t know or are unsure of your response to an item, give your best estimate.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| 1. I feel tense or ‘wound up’ | □ Most of the time | □ A lot of the time | □ From time to time, occasionally | □ Not at all |
| 2. I still enjoy the things I used to enjoy | □ Definitely as much | □ Not quite so much | □ Only a little | □ Hardly at all |
| 3. I get a sort of frightened feeling as if something awful is about to happen | □ Very definitely and quite badly | □ Yes, but not too much | □ A little, but it doesn’t worry me | □ Not at all |
| 4. I can laugh and see the funny side of things | □ As much as I always could | □ Not quite so much now | □ Definitely not so much now | □ Not at all |
| 5. Worrying thoughts go through my mind | □ A great deal of the time | □ A lot of the time | □ From time to time but not too often | □ Only occasionally |
| 6. I feel cheerful | □ Not at all | □ Not often | □ Sometimes | □ Most of the time |
| 7. I can sit at ease and feel relaxed | □ Definitely | □ Usually | □ Not often | □ Not at all |
| 8. I feel as if I am slowed down | □ Nearly all the time | □ Very often | □ Sometimes | □ Not at all |
| 9. I get sort of frightened feeling like ‘butterflies in my stomach’ | □ Not at all | □ Occasionally | □ Quite often | □ Very often |
| 10. I have lost interest in my appearance | □ Definitely | □ I don’t take so much care as I should | □ I may not take quite as much care | □ I take just as much care as ever |
| 11. I feel restless as if I have to be on the move | □ Very much indeed | □ Quite a lot | □ Not very much | □ Not at all |
| 12. I look forward with enjoyment to things | □ As much as I ever did | □ Rather less than I used to | □ Definitely less than I used to | □ Hardly at all |
| 13. I get sudden feelings of panic | □ Very often indeed | □ Quite often | □ Not very often | □ Not at all |
| 14. I can enjoy a good book or radio or TV program | □ Often | □ Sometimes | □ Not often | □ Very seldom |

**A3. Your Thoughts and Feelings about Breast Cancer**

*We wish to know how frequently the following thoughts and feelings about cancer happened for you* ***during the past 7 days****. For each statement, please circle one answer (not at all, rarely, sometimes, or often).*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Not At All** | **Rarely** | **Sometimes** | **Often** |
| 1. I thought about breast cancer when I didn't mean to | 0 | 1 | 2 | 3 |
| 2. I tried to remove breast cancer from my memory | 0 | 1 | 2 | 3 |
| 3. I had waves of strong feelings about breast cancer | 0 | 1 | 2 | 3 |
| 4. I stayed away from reminders of breast cancer | 0 | 1 | 2 | 3 |
| 5. I tried not to talk about breast cancer | 0 | 1 | 2 | 3 |
| 6. Pictures about breast cancer popped into my mind | 0 | 1 | 2 | 3 |
| 7. Other things kept making me think about breast cancer | 0 | 1 | 2 | 3 |
| 8. I tried not to think about breast cancer | 0 | 1 | 2 | 3 |

**A4. Cancer Genetic Testing**

*The next questions ask about cancer genetic testing.*

1. Have you or a blood relative ever had a genetic test for hereditary cancer (for example, a test for mutations in the BRCA1 or BRCA2 genes)?

* Yes
* No 🡪 *go to Section A5.*
* Don’t know 🡪 *go to Section A5.*

***If Yes:*** a. Did the genetic test identify any genetic mutations for hereditary cancer in you or a blood relative?

* Yes
* No
* Don’t know

**A5. Your Thoughts on Breast Cancer Risk**

*In the past week, please indicate whether you have experienced each of the following feelings regarding your risk for breast cancer. For each statement, please circle one answer.*

|  |  | **Never** | **Rarely** | **Sometimes** | **Often** |
| --- | --- | --- | --- | --- | --- |
| 1. | In the past week, I have felt uncertain about  my risk for breast cancer | 0 | 1 | 2 | 3 |
| 2. | In the past week, I have felt uncertain about what my risk for breast cancer means for my child(ren) and/or family’s risk of developing breast cancer | 0 | 1 | 2 | 3 |
| 3. | In the past week, I have felt uncertain about what my choices are for early detection/screening or prevention of breast cancer | 0 | 1 | 2 | 3 |

*Questions 4-13 ask your opinion about things you can do to prevent or delay getting breast cancer. If you have already had breast cancer, please tell us what you think about preventing or delaying getting breast cancer again, which for this survey means getting another breast cancer.*

4a.  Have you had both of your breasts removed (double mastectomy)?

* Yes 🡪 *go to Section A6.*
* No  🡪 *go to Question 4b.*

4b. How much can you do to reduce your chances of getting breast cancer (again)? *(Check one answer)*

* Nothing at all
* A little bit
* Moderate amount
* Quite a bit
* Very much
* Don’t know

*For each statement, please circle one answer.*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **Disagree Strongly** | **Disagree** | **Neither Agree Nor Disagree** | **Agree** | **Agree Strongly** |
| 5. | I believe that I can do things to delay the onset of breast cancer (again) | 1 | 2 | 3 | 4 | 5 |
| 6. | I think that my genes will determine if I get breast cancer (again) regardless  of my actions to prevent it | 1 | 2 | 3 | 4 | 5 |
| 7. | If I lead a healthy lifestyle, I will prevent  or delay breast cancer | 1 | 2 | 3 | 4 | 5 |
| 8. | If I have a mutation in a breast cancer gene (for example, in the BRCA1 or BRCA2 gene) leading a healthy lifestyle will prevent  or delay breast cancer | 1 | 2 | 3 | 4 | 5 |
| 9. | Exercise is effective in preventing  or delaying breast cancer | 1 | 2 | 3 | 4 | 5 |
| 10. | Stress management is effective in preventing or delaying breast cancer | 1 | 2 | 3 | 4 | 5 |
| 11. | Social support (family and friends) is effective in preventing or delaying breast cancer | 1 | 2 | 3 | 4 | 5 |
| 12. | A healthy diet is effective in preventing  or delaying breast cancer | 1 | 2 | 3 | 4 | 5 |
| 13. | Vitamin supplements are effective in preventing or delaying breast cancer | 1 | 2 | 3 | 4 | 5 |

**A6. Your Opinions Regarding Personal Genetics**

*For several years it has been possible to examine a small sample of blood to look for the presence of genetic changes in single genes known to be associated with a particular type of disease; for example, BRCA1 and BRCA2 which are associated with increased risk of breast and ovarian cancer. Recent advances now make it possible to look for genetic abnormalities that are associated with many diseases in a single blood test, called a gene panel. Soon it will even be possible to have a test that looks at all of your genes, a test that will tell you everything that is known about the genes that might influence your health. We are interested in your opinion about your personal genetic status.*

1. What information would be helpful for you in making decisions about whether to learn about your personal genetic information? *(Please check the top three items that are most important to you)*

* Details about the test itself – how is it done, what is it looking for
* Details about what exactly is involved in having the test done
* Details about any harms related to having the test
* Details about the accuracy of the test
* Details about the way in which the information will be delivered
* Details about how understandable the information obtained from the test is
* Details about my level of risk if the test is positive
* Details about how serious the diseases included in the test are
* Details about steps I can take to minimize risk for getting the disease
* Details about age I might develop the disease
* Details about how the test will help someone in my family
* Other
* None

2. If you were to have access to your personal genetic information, how much of it would you want to know? I would want to receive genetic information about ….. *(Check all that are true for you)*

* Everything found
* Cancers in my family
* Other diseases in my family
* Diseases where the risk is very high
* Diseases that are serious
* Diseases that I can do something about
* Other
* I would not want any genetic information

3. In your opinion, what are the advantages to having access to extensive personal genetic information? *(Check the top three items that are most important to you)*

* To gain more knowledge about my health
* To explain what is going on in my family
* To take control of my health
* To know what symptoms to take seriously
* To know how to plan for the future
* To be able to make lifestyle changes
* To help others in the family
* Other
* None

4. In your opinion, what are the disadvantages to having access to extensive personal genetic information? *(Check the top three items that are most important to you)*

* Information could make you hyper-concerned and worried about the future
* Finding out about things you don’t want to know
* Feeling guilty about passing down a gene that causes disease
* Feeling sad about passing down a gene that causes disease
* Complicated information might be overwhelming
* The results could leave me feeling helpless
* The results could cause worry in the family
* Other
* None

5. Are there any barriers to you in terms of accessing your personal genetic information?

*(Check the top three items that are most important to you)*

* Cost of the test
* Time it takes to get the test
* Convenience of getting the test
* Pain of the test
* Fear of loss of insurance coverage
* Fear of discrimination from jobs
* Other
* None

6. If my personal genetic information indicates a risk for a disease, the lifestyle changes I would consider making are: *(Check the top three items that are most important to you)*

* Changes in eating habits
* Changes in exercise
* Stop smoking
* Lose weight
* Chemoprevention (taking medicines to reduce my risk of cancer or other diseases)
* Other
* None

7. Who would you share your personal genetic information with? *(Check all that are true for you)*

* Immediate family
* Extended family
* Young members of the family
* My partner
* Would decide on a case by case basis
* Friends
* Health care providers
* Other
* None

8. How much of your information would you share with your immediate family members? *(Check one answer)*

* All of it
* Only the information that would help them
* Other
* None of it

9. What types of resources would your family (or you) find most helpful to deal with this information? *(Check the top three items that are most important to you)*

* Genetic counselors
* Support of family
* Support of health care provider
* Written information
* Video
* Links to more information
* Support group
* Other
* None

*For each statement, please circle one answer.*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **Disagree Strongly** | **Disagree** | **Neither Agree Nor Disagree** | **Agree** | **Agree Strongly** |
| 10. | I would share my genetic information with my family members | 1 | 2 | 3 | 4 | 5 |
| 11. | I would be willing to make lifestyle changes based on my personal genetic information | 1 | 2 | 3 | 4 | 5 |
| 12. | I would make lifestyle changes if the information indicated that I might get cancer | 1 | 2 | 3 | 4 | 5 |
| 13. | I would make lifestyle changes if the information indicated that I might get diabetes | 1 | 2 | 3 | 4 | 5 |
| 14. | I would make lifestyle changes if the information indicated that I am at increased risk of getting other diseases | 1 | 2 | 3 | 4 | 5 |
| 15. | I would have concerns about the privacy of the information | 1 | 2 | 3 | 4 | 5 |
| 16. | I would have concerns about the confidentiality of the information | 1 | 2 | 3 | 4 | 5 |
| 17. | I would have concerns about possible insurance discrimination | 1 | 2 | 3 | 4 | 5 |

**SECTION B: MEDICAL HISTORY AND LIFESTYLE**

**B1. Mammograms, Breast Exams, and Breast MRI**

*The next questions ask about mammograms, breast exams, and breast MRIs (Magnetic Resonance Imaging) in the past 12 months.*

1. Have you had surgery to remove both of your breasts?

* Yes 🡪 *go to Section B2, Question 1b.*
* No 🡪 *go to Question 2.*

2. In the past 12 months, have you had a mammogram?

* Yes
* No 🡪 *go to Question 3.*

***If Yes:***  a. When did you have your most recent mammogram? \_\_\_\_\_\_\_\_\_ / \_\_\_\_\_\_\_\_

*Month Year*

3. In the past 12 months, have you performed breast self-examination?

* Yes
* No 🡪 *go to Question 4.*

***If Yes:***  a. In the past 12 months, approximately how many times have you performed breast self-examination?

\_\_\_\_\_\_ Times

4. In the last 12 months, have you had a clinical breast exam by a doctor, nurse or other health professional?

* Yes
* No 🡪 *go to Question 5.*

***If Yes:***  a. When did you have your most recent clinical breast exam? \_\_\_\_\_\_\_\_\_ / \_\_\_\_\_\_\_\_

*Month Year*

5. In the last 12 months, have you had a breast MRI or magnetic resonance imaging of the breast?

* Yes
* No 🡪 *go to Section B2.*

***If Yes:***  a. When did you have your most recent breast MRI? \_\_\_\_\_\_\_\_\_ / \_\_\_\_\_\_\_\_

*Month Year*

**B2. Surgeries: Breast and Ovary Removal**

*The next questions ask about breast and ovary removal. We have asked these questions in previous questionnaires and would like to get an update on additional surgeries.*

1. Have you ever had a mastectomy, which is the complete removal of one or both breasts?

* Yes
* No 🡪 *go to Question 2.*
* Don’t know 🡪 *go to Question 2.*

***If Yes:***  a. Which breasts were removed?

* Right only
* Left only
* Both right and left

***If your right breast was removed:***

b. At what age was your right breast removed ? \_\_\_\_\_\_\_ Years

c. Why was your right breast removed?

* To treat breast cancer
* To prevent getting cancer in my right breast
* Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

***If your left breast was removed:***

d. At what age was your left breast removed ? \_\_\_\_\_\_\_ Years

e. Why was your left breast removed?

* To treat breast cancer
* To prevent getting cancer in my left breast
* Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2. Have you ever had one or both ovaries removed?

* Yes
* No 🡪 *go to Section B3.*
* Don’t know 🡪 *go to Section B3.*

***If Yes:*** a. Did you have one or both ovaries removed?

* One
* Both
* Don’t know

b. At what age was your first ovary removed ? \_\_\_\_\_\_\_ Years

c. Why was your first ovary removed?

* To treat ovarian cancer
* To prevent cancer in that ovary
* As part of treatment for breast cancer
* As part of prevention of breast cancer
* Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

***If both ovaries were removed:***

d. At what age was your second ovary removed ? \_\_\_\_\_\_\_ Years

e. Why was your second ovary removed?

* To treat ovarian cancer
* To prevent cancer in that ovary
* As part of treatment for breast cancer
* As part of prevention of breast cancer
* Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**B3. Medications for Risk Reduction**

1. Chemoprevention means taking a drug that reduces the chance of developing breast cancer in the first place. Have you ever taken tamoxifen, raloxifene (Evista) or exemestane (Aromasin) to reduce the risk of breast cancer? Please do not include these medications if they were taken for treatment of your breast cancer.

Tamoxifen € Yes € No 🡪 *go to Section B4.* € Don’t know 🡪 *go to Section B4.*

Evista € Yes € No 🡪 *go to Section B4.* € Don’t know 🡪 *go to Section B4.* Aromasin € Yes € No 🡪 *go to Section B4.* € Don’t know 🡪 *go to Section B4.*

***If Yes to any:***

a.How old were you when you first started using any of these medications to reduce the risk of breast cancer?

\_\_\_\_ Years

b. In total, for how many months or years have you taken these medications?

\_\_\_\_ Months OR \_\_\_\_ Years

c. Are you currently taking any of these medications to reduce the risk of breast cancer?

* Yes 🡪 *go to Section B4.*
* No
* Don’t know 🡪 *go to Section B4.*

***If No:*** d. At what age did you STOP taking these medications?

\_\_\_\_ Years

**B4. Lifestyle Behaviors in the Past Year**

*The next questions ask about your typical lifestyle behaviors in the past year.*

In the past year, how much of each beverage did you usually drink? *(For each beverage, check one answer)*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Drinks per week in past year** | | | | | | | |
| None or Never | less than 1 per week | 1-2  per week | 3-4  per week | 5-6  per week | 7  per week | 8-14 per week | 15 or more per week |
| 1. Beer  (1 Drink = 1 bottle, can or glass) | □ | □ | □ | □ | □ | □ | □ | □ |
| 2. Wine, Champagne  (1 Drink = 1 glass) | □ | □ | □ | □ | □ | □ | □ | □ |
| 3. Cocktails, Liquor  (1 Drink = 1 cocktail, shot, or mixed drink of liquor) | □ | □ | □ | □ | □ | □ | □ | □ |

**If “none or never”** to beer, wine, champagne, cocktails and liquor: 🡪 *go to Question 5.*

4. In the past year, have you had 4 or more alcoholic beverages within a two-hour period? *(Check one answer)*

* Never
* 1-2 days in the past year
* 3-11 days in the past year
* One day a month
* 2-3 days a month
* One day a week
* More than one day a week

5. In the past year, how many cigarettes did you smoke in a typical day? *(Check one answer)*

* None, never have smoked
* Not in the past year, but I smoked in the past
* 1-4
* 5-9
* 10-14
* 15-19
* 20-29
* 30-39
* 40 or more

6. In the past year, did you participate in strenuous exercise activities or sports (such as swimming laps, aerobics, running, jogging, basketball, cycling on hills)?

* Yes
* No 🡪 *go to Question 7.*

***If Yes:***  a. On average, how many hours a week did you do strenuous exercise activities or sports in the past year? *(Please circle one answer)*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Hours per week in past year** | | | | | | | |
| ½ | 1 | 1 ½ | 2 | 3 | 4-6 | 7-10 | 11 or more |

b. In the past year, for how many months did you do strenuous exercise activities or sports? *(Please circle one answer)*

|  |  |  |  |
| --- | --- | --- | --- |
| **Number of months in past year** | | | |
| 1-3 | 4-6 | 7-9 | 10-12 |

7. In the past year, did you participate in moderate exercise activities or sports (such as brisk walking, golf, cycling on level streets, recreational tennis, yoga, volleyball)?

* Yes
* No 🡪 *go to Question 8.*

***If Yes:***  a. On average, how many hours a week did you do moderate exercise activities or sports in the past year? *(Please circle one answer)*

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Hours per week in past year** | | | | | | | |
| ½ | 1 | 1 ½ | 2 | 3 | 4-6 | 7-10 | 11 or more |

b. In the past year, for how many months did you do moderate exercise activities or sports? *(Please circle one answer)*

|  |  |  |  |
| --- | --- | --- | --- |
| **Number of months in past year** | | | |
| 1-3 | 4-6 | 7-9 | 10-12 |

In the past year, on average, how often did you spend time in the following activities?*(For each activity, check one answer for hours per day, and check one answer for days per week)*

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Average hours per day in past year** | | | | | | | | **Days per week**  **in past year** | | | |
|  | None | Less than 1 | 1 | 2 | 3-4 | 5-6 | 7-9 | 10 or more | 1 | 2-3 | 4-5 | 6-7 |
| 8. Housework | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 9. Gardening | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 10. Standing or walking at home or at work | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 11. Sitting | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 12. Sleeping | □ | □ | □ | □ | □ | □ | □ | □ |  | | | |
| 13. Watching TV | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 14. Resting or napping | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ | □ |

**B5. Your Height and Weight**

*The following questions are about your height and weight.*

1. What is your current height? \_\_\_ Feet \_\_\_Inches OR \_\_\_\_\_ Centimeters

2. What is your current weight? \_\_\_\_ Pounds OR \_\_\_\_ Kilograms

3. What was your weight at age 18? \_\_\_\_ Pounds OR \_\_\_\_ Kilograms

4. What is the MOST you have ever weighed since age 18? *(Do not include times when you were pregnant)*

\_\_\_\_ Pounds OR \_\_\_\_ Kilograms

5. Excluding times when you were pregnant, what was your usual weight when you were in your 20s, 30s, 40s, or 50s. (*Check ‘Not applicable’ if you have not yet reached that age)*

In your 20s: \_\_\_\_ Pounds OR \_\_\_\_ Kilograms □ Not applicable

In your 30s: \_\_\_\_ Pounds OR \_\_\_\_ Kilograms □ Not applicable

In your 40s: \_\_\_\_ Pounds OR \_\_\_\_ Kilograms □ Not applicable

In your 50s: \_\_\_\_ Pounds OR \_\_\_\_ Kilograms □ Not applicable

6. How many times in your life did you intentionally lose 10 or more pounds (4.5 kg)? *(Check one answer, do not include times when you were pregnant or sick)*

* None, or never 🡪 *go to Question 8.*
* 1-2
* 3-5
* 6-10
* More than 10 times

7. How many times in your life have you regained as much as 10 pounds (4.5 kg) that you previously had lost? *(Check one answer)*

* None, or never
* 1-2
* 3-5
* 6-10
* More than 10 times

8. What is the most weight you have ever lost on purpose in your life? (If none, put 0)

\_\_\_\_ Pounds OR \_\_\_\_ Kilograms

9. What was your weight one year ago?

\_\_\_\_ Pounds OR \_\_\_\_ Kilograms

10. Over the last year has your weight changed, excluding a change due to pregnancy?

* Yes
* No 🡪 *go to question 11.*

***If Yes:*** a. Did you gain weight or lose weight? *(Check all that apply)*

* Gained weight
* Lost weight

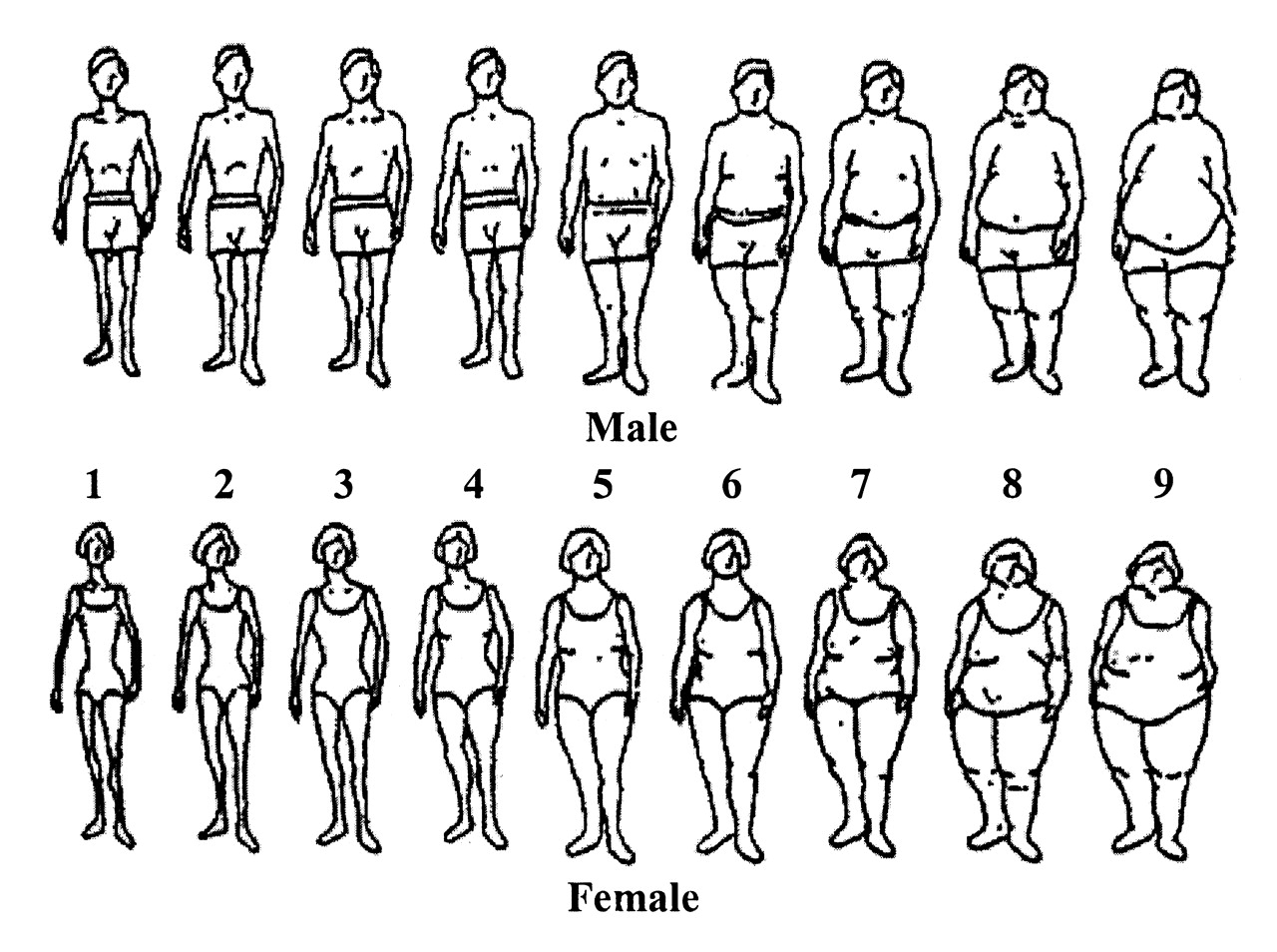
b. Was this weight change intentional or unintentional?

* Intentional weight gain
* Unintentional weight gain
* Intentional weight loss
* Unintentional weight loss

11. When you gain weight, where on your body do you mostly add the weight? *(Check one answer)*

* Waist or upper body
* Hips or upper thighs
* Evenly over body
* I don’t gain weight

Which of these pictures do you think best represents your body type at each age? *(For each age, please circle one answer. Circle “N/A” for ‘not applicable’ if you have not yet reached that age)*

**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 12. Currently | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 13. At age 10 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 14. At age 20 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 15. At age 30 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 16. At age 40 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 17. At age 50 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |
| 18. At age 60 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | N/A |

**B6. Medications, Vitamins, and Herbal Preparations**

*The next questions are about your regular use of certain medications in the past 10 years. We are only interested in medications you took at least two days a week.*

1. In the past 10 years, did you take any of the medications listed below at least two days a week?

* Yes
* No 🡪 *go to question 7.*

***If Yes:*** a. For how many years and how many days per week did you take any of the medications listed below? *(For each medication taken at least two days a week, check one answer for the number of years taken).*

1. Are you currently taking any of the medications listed below at least two days a week?

* Yes
* No 🡪 *go to question 7.*

***If yes:*** a. How many days a week are you currently taking the medication? *(check one answer in the table below)*

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Number of years taken** | | | | | | **CURRENT USERS:**  **# days taken per week** | | |
|  | **Less than**  **1 year** | **1 year** | **2**  **years** | **3-4 years** | **5-9**  **years** | **10 years**  **or longer** | **2-3** | **4-6** | **Every day** |
| 3. Regular Strength Aspirin (Anacin, Bufferin, Excedrin) | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 4. Baby Aspirin | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 5. Acetaminophen (Tylenol, Anacin-3, Panadol, Aspirin Free Excedrin) | □ | □ | □ | □ | □ | □ | □ | □ | □ |
| 6. Ibuprofen (Advil, Motrin, Nuprin) | □ | □ | □ | □ | □ | □ | □ | □ | □ |

*The next questions are about your regular use of vitamins in the past 10 years. We are only interested in vitamins you took at least two days a week.*

7. In the past 10 years, did you take any vitamins at least two days a week?

* Yes
* No 🡪 *go to question 19.*

***If Yes:*** a. For how many years did you take any of the vitamins listed below? *(For each vitamin taken at least two days a week, check one answer for the number of years taken).*

1. Are you currently taking any of the vitamins listed below at least two days a week?

* Yes 🡪 *in the table below, check “yes” for each vitamin you are currently taking at least two days a*

*week*

* No 🡪 *go to question 19.*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Number of years taken** | | | | | | **Currently taking at least**  **two days a week** | |
|  | **Less than 1 year** | **1**  **year** | **2 years** | **3-4 years** | **5-9 years** | **10 years**  **or longer** | **Yes** | **No** |
| 9. Multivitamin | □ | □ | □ | □ | □ | □ | □ | □ |
| 10. B vitamin complex | □ | □ | □ | □ | □ | □ | □ | □ |
| 11. Vitamin A | □ | □ | □ | □ | □ | □ | □ | □ |
| 12. Vitamin C | □ | □ | □ | □ | □ | □ | □ | □ |
| 13. Vitamin D | □ | □ | □ | □ | □ | □ | □ | □ |
| 14. Vitamin E | □ | □ | □ | □ | □ | □ | □ | □ |
| 15. Calcium | □ | □ | □ | □ | □ | □ | □ | □ |
| 16. Folic Acid | □ | □ | □ | □ | □ | □ | □ | □ |
| 17. Other *(specify)*  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | □ | □ | □ | □ | □ | □ | □ | □ |
| 18. Other *(specify)*  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | □ | □ | □ | □ | □ | □ | □ | □ |

*The next questions are about your regular use**of herbal preparations in the past 10 years. We are only interested in herbal preparations you took at least two days a week.*

1. In the past 10 years, did you take any of the herbal preparations listed below at least two days a week?

* Yes
* No 🡪 *go to Section C.*

***If Yes:*** a. For how many years did you take any of the herbal preparations listed below? *(For each herbal preparation taken at least two days a week, check one answer for the number of years taken).*

1. Are you currently taking any of the herbal preparations listed below at least two days a week?

* Yes 🡪 *in the table below, check “yes” for each herbal preparation you are currently taking at least*

*two days a week*

* No 🡪 *go to Section C.*

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Number of years taken** | | | | | | **Currently taking at least**  **two days a week** | |
|  | **Less than 1 year** | **1**  **year** | **2 years** | **3-4 years** | **5-9 years** | **10 or more years** | **Yes** | **No** |
| 21. Soy estrogen pills | □ | □ | □ | □ | □ | □ | □ | □ |
| 22. Dong quai (such as Rejuvex) | □ | □ | □ | □ | □ | □ | □ | □ |
| 23. Natural progesterone cream or wild yam cream | □ | □ | □ | □ | □ | □ | □ | □ |
| 24. Black cohosh (such as Remifemin) | □ | □ | □ | □ | □ | □ | □ | □ |
| 25. Flaxseed or linseed oil | □ | □ | □ | □ | □ | □ | □ | □ |
| 26. CoQ10 | □ | □ | □ | □ | □ | □ | □ | □ |
| 27. Echinacea | □ | □ | □ | □ | □ | □ | □ | □ |
| 28. Gingko Biloba | □ | □ | □ | □ | □ | □ | □ | □ |
| 29. Ginseng | □ | □ | □ | □ | □ | □ | □ | □ |
| 30. Omega-3 fish oils | □ | □ | □ | □ | □ | □ | □ | □ |
| 31. Glucosamine Chondroitin | □ | □ | □ | □ | □ | □ | □ | □ |
| 32. Green Tea | □ | □ | □ | □ | □ | □ | □ | □ |
| 33. St. John's Wort | □ | □ | □ | □ | □ | □ | □ | □ |
| 34. Probiotics | □ | □ | □ | □ | □ | □ | □ | □ |
| 35. Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | □ | □ | □ | □ | □ | □ | □ | □ |
| 36. Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | □ | □ | □ | □ | □ | □ | □ | □ |

**SECTION C: HEALTH INFORMATION UPDATES**

**C1. Your Personal Health History**

*The next questions are about health conditions you may have been diagnosed with by a doctor.*

1. Have you ever been diagnosed by a doctor with any of the conditions listed below?

* Yes
* No 🡪 *go to question Section C2.*

***If Yes:*** *Please check each condition you have been diagnosed with and write your age when you were first diagnosed.*

|  |  |  |
| --- | --- | --- |
|  | * 1. Have you ever been diagnosed with this condition   *(check all that apply)* | b. How old were you when you were first diagnosed? |
| 2. Diabetes | □ |  |
| 3. Type 1 diabetes (insulin is prescribed for me) | □ |  |
| 4. Type 2 diabetes (insulin is NOT prescribed for me) | □ |  |
| 5. Diabetes during pregnancy (Gestational diabetes) | □ |  |
| 6. Heart attack or myocardial infarction | □ |  |
| 7. Heart failure | □ |  |
| 8. Operation to unclog or bypass the arteries in legs | □ |  |
| 9. Stroke, cerebrovascular accident, clot or bleeding in brain, or TIA | □ |  |
| 10. Angina or angina pectoris | □ |  |
| 11. Coronary heart disease | □ |  |
| 12. Coronary bypass, angioplasty, or stent | □ |  |
| 13. Hypertension or high blood pressure | □ |  |
| 14. Hepatitis, cirrhosis, or serious liver damage | □ |  |
| 15. High cholesterol | □ |  |
| 16. Osteoporosis | □ |  |
| 17. Thyroid Disorder | □ |  |
| 18. Grave's disease/ Hyperthyroidism | □ |  |
| 19. Hypothyroidism | □ |  |
| 20. Hyperparathyroidism | □ |  |
| 21. Endometriosis | □ |  |
| 22. Confirmed by surgery | □ Yes □ No |  |
| 23. Fibroids | □ |  |
| 24. Polycystic Ovary Syndrome (PCOS) | □ |  |

**C2. New Cancer Diagnosis**

*The next questions ask about new cancer diagnoses you may have had since you last completed an interview with us in <DATE>.*

1. Since <DATE>, have you had a diagnosis of a new breast cancer (i.e., a breast cancer that is not a recurrence of a previous breast cancer)?

* Yes
* No 🡪 *go to Question 2.*
* Don’t know 🡪 *go to Question 2.*

***If Yes:***  a. Was this an invasive breast cancer?

* Yes
* No
* Don’t know

b. Which breast was the new cancer in? *(Check one answer)*

* Right
* Left
* Both

c. How old were you when this new breast cancer was diagnosed?

\_\_\_\_ Years

2. Since <DATE>, have you had a recurrence of breast cancer?

* Yes
* No 🡪 *go to Question 3.*
* Don’t know 🡪 *go to Question 3.*

***If Yes:***  a. Where was the recurrence? *(Check as many as apply)*

* Right breast
* Left breast
* Both breasts
* Other site, specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don’t know

b. How old were you when this recurrence was diagnosed?

\_\_\_\_ Years

3. 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)? *(Check one answer)*

* Yes
* No 🡪 *go to Section C3.*
* Don’t know 🡪 *go to Section C3.*

***If Yes:***  a. Where in the body did this cancer begin?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

b. How old were you when this cancer was diagnosed?

\_\_\_\_ Years

c. After that diagnosis, have you had any other diagnosis of cancer?

* Yes
* No 🡪 *go to Section C3.*
* Don’t know 🡪 *go to Section C3.*

***If Yes:***  d. Where in the body did this cancer begin?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

e. How old were you when this cancer was diagnosed?

\_\_\_\_ Years

**C3. Family Cancer History**

*The next questions ask about new cancers diagnosed in your blood relatives since the last update in* ***<DATE>.***

1. 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).

* Yes
* No 🡪 *go to Question 2.*
* Don’t know 🡪 *go to Question 2.*

***If Yes:***  a. Which blood relative was diagnosed, with what cancer, and at what age?

|  |  |  |  |
| --- | --- | --- | --- |
| **Name** | **Relationship to you (for example mother’s father, cousin on father’s side)** | **Type of Cancer** | **Age at diagnosis** |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

2. 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).

* Yes
* No 🡪 *go to Section C4.*
* Don’t know 🡪 *go to Section C4.*

***If Yes:***  a. Which blood relative died, from what cause, and at what age?

|  |  |  |  |
| --- | --- | --- | --- |
| **Name** | **Relationship to you (for example mother’s father, cousin on father’s side)** | **Cause of death** | **Age at death** |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |
|  |  |  |  |

**C4. Pregnancies**

*The next questions ask about new pregnancies you may have had since you last completed an interview with us in* ***<DATE>****.*

1. Since <DATE>, have you been pregnant?

* Yes
* No 🡪 *go to Section C5.*
* Don’t know 🡪 *go to Section C5.*

***If Yes:*** a. Are you currently pregnant?

* Yes
* No
* Don’t know

b. Since <DATE>, how many pregnancies have you had? \_\_\_\_\_ Pregnancies

*For each pregnancy since <DATE>, please fill in the column(s) below:*

|  |  |  |  |
| --- | --- | --- | --- |
|  | **1ST PREGNANCY** | **2ND PREGNANCY** | **3RD PREGNANCY** |
| c. How long was this pregnancy?  *(Check one answer)* | □ 3 months or under  □ 4 to 6 months  □ 7 months or more  □ Don’t know | □ 3 months or under  □ 4 to 6 months  □ 7 months or more  □ Don’t know | □ 3 months or under  □ 4 to 6 months  □ 7 months or more  □ Don’t know |
| d. What was the outcome of this pregnancy?  *(Check one answer)* | □ Currently pregnant  □ Live birth  □ Stillbirth  □ Miscarriage or  spontaneous abortion  □ Tubal pregnancy  □ Induced abortion  □ Don’t know | □ Currently pregnant  □ Live birth  □ Stillbirth  □ Miscarriage or  spontaneous abortion  □ Tubal pregnancy  □ Induced abortion  □ Don’t know | □ Currently pregnant  □ Live birth  □ Stillbirth  □ Miscarriage or  spontaneous abortion  □ Tubal pregnancy  □ Induced abortion  □ Don’t know |
| *Complete questions e - g only if the outcome was a live birth* | | | |
| e. What was the sex of this baby (these babies)? | \_\_\_\_ # of Boys  \_\_\_\_ # of Girls | \_\_\_\_ # of Boys  \_\_\_\_ # of Girls | \_\_\_\_ # of Boys  \_\_\_\_ # of Girls |
| f. Did you breast feed this baby (these babies)?  *(Check one answer)*  ***If Yes:***  g. For how many months did you breast feed this baby (these babies)?  *(Check one answer)* | □ Yes  □ No  □ Don’t know  □ Under 1 month  □ 1 to 5 months  □ 6 to 11 months  □ 12 to 23 months  □ 24 months or longer  □ Don’t know | □ Yes  □ No  □ Don’t know  □ Under 1 month  □ 1 to 5 months  □ 6 to 11 months  □ 12 to 23 months  □ 24 months or longer  □ Don’t know | □ Yes  □ No  □ Don’t know  □ Under 1 month  □ 1 to 5 months  □ 6 to 11 months  □ 12 to 23 months  □ 24 months or longer  □ Don’t know |

**C5. Menstruation and Menopause**

*The next questions ask about your menstrual periods.*

1. Have you had a period in the last 12 months?

* Yes 🡪 *go to Section C6.*
* No

***If No:***  a. Why did your period stop? *(Check all that apply and provide ages where appropriate)*

* Natural menopause (periods stopped by themselves)

How old were you? \_\_\_\_\_ Years

* Hysterectomy (womb or uterus removed)

How old were you? \_\_\_\_\_ Years

* Both ovaries removed

How old were you? \_\_\_\_\_ Years

* Radiation or chemotherapy

How old were you? \_\_\_\_\_ Years

* Strenuous exercise
* Illness
* Pregnancy
* Breast feeding
* Don’t know
* Other *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**C6. Birth Control and Menopausal Hormones**

*The next questions ask about your use of birth control.*

1. Since <DATE>, have you used birth control pills or other hormonal contraceptives (implants or injections)?

* Yes
* No 🡪 *go to Question 3.*
* Don’t know 🡪 *go to Question 3.*

***If Yes:***  a. Are you currently taking birth control pills or hormonal contraceptives?

* Yes 🡪  *go to Question 2.*
* No

***If No:*** b. How old were you when you last took birth control pills or other

hormonal contraceptives?

\_\_\_\_ Years

1. Since <DATE>, for how many months or years have you taken birth control pills or hormonal contraceptives in total?

\_\_\_\_ Months OR \_\_\_\_ Years

*The next questions are about your use of menopausal hormones.*

**3.** Since <DATE>, have you taken estrogen, progesterone or other female hormones for menopause, that is, prescription hormone replacement therapy or HRT? Please include pills, injections or skin patches but do not include products inserted into the vagina.

* Yes
* No 🡪 *go to* ***END OF SURVEY*** *at the bottom of this page.*
* Don’t know 🡪 *go to* ***END OF SURVEY*** *at the bottom of this page.*

***If Yes:*** a. Were you still having periods when you first took estrogen, progesterone or other female hormones?

* Yes
* No
* Don’t know

b. Since <DATE>, for how many months or years have you taken female hormones or hormone replacement therapy?

\_\_\_\_ Months OR \_\_\_\_ Years

c. What were the female hormones you MAINLY used during that time? *(Check one answer)*

* Progesterone only
* Estrogen only
* Progesterone and estrogen
* Only know brand name *(specify)* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Don’t know

d. Are you currently taking female hormones for menopause?

* Yes
* No
* Don’t know

***If No:*** e. How old were you when you last took female hormones for menopause?

\_\_\_\_ Years

f. Why did you stop taking female hormones for menopause? (*Specify)*

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## END OF SURVEY

**THANK YOU!**

Thank you so much for taking the time to complete this survey.

We greatly appreciate your continued participation in the Breast Cancer Family Registry.

**Please mail back the survey in the self-addressed and stamped return envelope.**