Breast Cancer Family Registry
Follow-up Questionnaire

PAR2 Version V.2 – 05/2019

Thank you for taking the time to complete this questionnaire. We would like to ask you questions, some of which are new, and some of which are updates to previously asked questions. These questions are about factors that may or may not be related to breast cancer risk. Your responses could also be used to answer questions about other cancers, such as bowel and ovarian cancers.

Section A

A1. General Information

1. What is your date of birth?

_____/______/_______
Month Day Year

2. On what date did you complete this questionnaire?

_____/______/_______
Month Day Year

A2. Screening

1. In the past 10 years, have you had a mammogram?

☐ Yes
☐ No → *go to Question 4*
☐ Don't know → *go to Question 4.*

2. How old were you when you had your most recent mammogram?

☐ ____________years
☐ Don't Know

3. Where was your most recent mammogram?

☐ Hospital
☐ Private Radiology clinic

4. In the past 10 years, have you had a breast MRI, which is magnetic resonance imaging of the breast?

☐ Yes
☐ No → *go to Question 6*
☐ Don't know → *go to Question 6.*

5. How old were you when you had your most recent breast MRI?

☐ ____________years
☐ Don't Know

6. Have you ever had a fecal occult blood test (FOBT) which is a stool testing kit usually done at home?

☐ Yes
☐ No → *go to Question 10*
☐ Don't know → *go to Question 10.*

7. How many FOBTs have you had in total?

☐ ____________FOBTs
☐ Don't Know

8. How old were you when you had your first FOBT?

☐ ____________years
☐ Don't Know

9. How old were you when you had your most recent FOBT?

☐ ____________years
☐ Don't Know

10. Have you ever had a colonoscopy?
In a colonoscopy, the entire large bowel is examined usually while you are under sedation (asleep). Preparation involves drinking fluids or taking pills to cleanse the bowel.

☐ Yes

☐ No → *go to Question 14*
☐ Don't know → *go to Question 14.*

11. How many colonoscopies have you had in total?

☐ ____________colonoscopies
☐ Don't Know

12. How old were you when you had your first colonoscopy?

☐ ____________years
☐ Don't Know

13. How old were you when you had your most recent colonoscopy?

☐ ____________years
☐ Don't Know

14. Have you <u>ever</u> had a sigmoidoscopy?
A sigmoidoscopy is similar to a colonoscopy but does not require extensive bowel preparation by drinking fluids. It is done with or without sedation after preparation of the bowel with an enema.

☐ Yes
☐ No → *go to Section B1*
☐ Don't know → *go to Section B1.*

15. How many sigmoidoscopies have you had in total?

☐ ____________sigmoidoscopies
☐ Don't Know

16. How old were you when you had your first sigmoidoscopy?

☐ ____________years
☐ Don't Know

17. How old were you when you had your most recent sigmoidoscopy?

☐ ____________years
☐ Don't Know

Section B

B1. Benign Breast Disease

1. Have you <u>ever</u> had a breast biopsy resulting in a diagnosis of <u>benign or non-cancerous</u> breast disease, such as lobular carcinoma *in situ* (LCIS), atypical ductal hyperplasia (ADH), or fibroadenoma?

☐ Yes
☐ No → *go to Section B2*
☐ Don't know → *go to Section B2.*

2. What type of benign breast disease did you have?
Mark all that apply.

☐ Lobular carcinoma *in situ* (LCIS)
☐ Atypical ductal hyperplasia (ADH)
☐ Hyperplasia with no atypia
☐ Fibroadenoma
☐ Other (specify)________________________
☐ Don't know

3. How old were you when you were <u>first</u> diagnosed with benign breast disease?

☐ ____ years
☐ Don't Know

B2. New Cancer Diagnosis

The next questions ask about new cancer diagnoses you may have had since **<u>«B2 Date»</u>**.

1. Since <u>«B2 Date»</u>, have you had a <u>diagnosis of a new breast cancer?</u>

☐ Yes
☐ No → *go to Question 5*
☐ Don't know → *go to Question 5.*

2. Was this an invasive breast cancer, or ductal carcinoma *in situ* (DCIS)?

☐ Invasive breast cancer
☐ Ductal carcinoma *in situ* (DCIS)
☐ Don't know

3. Which breast was the new cancer in? *Mark ONE answer.*

☐ Right
☐ Left
☐ Both

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

☐ ____ years
☐ Don't Know

5. Since «B2 Date», have you had a diagnosis of any other type of cancer besides breast cancer, including sarcoma, leukemia, lymphoma, or any other malignant tumor (including melanoma, but not other skin cancers)? *Mark ONE answer*.

- ☐ Yes
- ☐ No → *go to Section B3*
- ☐ Don't know → *go to Section B3.*

6. Where in the body did this cancer begin?

____

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

- ☐ ____ years
- ☐ Don't Know

8. After that diagnosis, have you had any other diagnosis of a new cancer?

- ☐ Yes
- ☐ No → *go to Section B3*
- ☐ Don't know → *go to Section B3.*

9. Where in the body did this cancer begin?

____

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

- ☐ ____ years
- ☐ Don't Know

B3. Surgeries

The next questions ask about surgical removal of breasts and ovaries. We have asked some of these questions in previous surveys and would like to get an update on additional surgeries.

1. Since «B3_Date» have you had a mastectomy, which is the complete removal of one or both breasts?

- ☐ Yes
- ☐ No → *go to Question 7*
- ☐ Don't know → *go to Question 7.*

2. Which breast(s) were removed?

- ☐ Right only
- ☐ Left only
- ☐ Both

If your right breast was removed:

3. At what age was your right breast removed?

- ☐ _____ years
- ☐ Don't Know

4. Why was your right breast removed?

- ☐ To treat breast cancer in my right breast
- ☐ To prevent getting cancer in my right breast
- ☐ Other (specify) ____________________

If your left breast was removed:

5. At what age was your left breast removed?

- ☐ _____ years
- ☐ Don't Know

6. Why was your left breast removed?

- ☐ To treat breast cancer in my left breast
- ☐ To prevent getting cancer in my left breast
- ☐ Other (specify) ____________________

7. Since «B3_7_Ref_Date» have you had one or both ovaries removed?

- ☐ Yes
- ☐ No → *go to Question 13*
- ☐ Don't know → *go to Question 13.*

8. Did you have one or both ovaries removed?

- ☐ One
- ☐ Both
- ☐ Don't know → *go to Question 13.*

9. At what age was your first ovary removed?

- ☐ ____ years
- ☐ *Don't Know*

10. Why was your first ovary removed? *Mark all that apply.*

- ☐ To treat ovarian cancer

☐ To prevent cancer in that ovary
☐ As part of treatment for breast cancer
☐ As part of prevention of breast cancer
☐ Non-cancerous condition (endometriosis, non-cancerous cyst)
☐ Other (specify) ____________________
☐ Don't know

If both ovaries were removed:

11. At what age was your second ovary removed?

☐ ____ years
☐ Don't Know

12. Why was your second ovary removed? *Mark all that apply.*

☐ To treat ovarian cancer
☐ To prevent cancer in that ovary
☐ As part of treatment for breast cancer
☐ As part of prevention of breast cancer
☐ Non-cancerous condition (for example endometriosis, non-cancerous cyst)
☐ Other (specify) ____________________
☐ Don't know

13. Since «B3_13_Ref_Date» have you had your uterus removed, also known as a hysterectomy?

☐ Yes
☐ No → *go to Question 16*
☐ Don't know → *go to Question 16.*

14. Why was your uterus removed? *Mark all that apply.*

☐ To treat uterine cancer
☐ To prevent cancer in the uterus
☐ As part of treatment for cervical cancer
☐ As part of treatment for ovarian cancer
☐ Non-cancerous condition (endometriosis, fibroid tumor, bleeding)
☐ Other (specify) _____________________
☐ Don't know

15. At what age was your uterus removed?

☐ ____ years
☐ Don't Know

16. Have you ever had one or both of your fallopian tubes removed?

☐ Yes – one tube removed
☐ Yes – both tubes removed
☐ No → *go to Section C1*
☐ Don't know → *go to Section C1.*

17. Why was your fallopian tube(s) removed? *Mark all that apply.*

☐ To prevent cancer
☐ To treat a cancer (ovarian, uterine, fallopian tube)
☐ Non-cancerous condition (endometriosis, ovarian cyst)
☐ Ectopic pregnancy
☐ Contraception
☐ Other (specify) _____________________
☐ Don't know

18. At what age was your first fallopian tube removed?

☐ ____ years
☐ Don't Know

19. At what age was your second fallopian tube removed?

☐ ____ years
☐ Don't Know

Section C

C1. Family Cancer History

The next questions ask about new cancers diagnosed in your blood relatives since **«C1 Date».**

1. **Since «C1 Date», have any of your blood relatives developed any cancers or tumors (including melanoma, but not other skin cancers)?** 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 3*
   ☐ Don't know → *go to Question 3.*

2. **Please complete the table below for those of your blood relatives who have been diagnosed with cancer.**

Last name/ Surname / Family name	First name	Sex	Relationship to you (e.g., my mother's father, cousin on my father's side)	Type of Cancer	Age or year of diagnosis

3. **Since «C3_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 know about (for example, cousins and their children).

   ☐ Yes
   ☐ No → *go to Section D1*
   ☐ Don't know → *go to Section D1.*

4. **Please complete the table below for those of your blood relatives who have died.**

Last name/ Surname / Family name	First name	Sex	Relationship to you (e.g., my mother's father, cousin on my father's side)	Cause of death	Age or year of death

Section D

D1. Medical History and Menstruation

The next questions ask about your general health and menstrual periods.

1. What is your current weight?

- ☐ ___ pounds OR ___Kilograms
- ☐ Don't Know

2. What is your current height?

- ☐ ___ feet and ___inches OR ___ meters and ___centimeters
- ☐ Don't Know

3.Have you <u>ever</u> had a tubal ligation (i.e., fallopian tubes tied or clipped to prevent pregnancy)?

- ☐ Yes
- ☐ No → *go to Question 5*
- ☐ Don't know → *go to Question 5.*

4. How old were you when you had the tubal ligation (tubes tied)?

- ☐ _______ years
- ☐ Don't Know

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

- ☐ Yes → *go to Section D2*
- ☐ No

6. Why did your periods stop? (*Mark all that apply).*

- ☐ Natural menopause (periods stopped by themselves)
- ☐ Hysterectomy (womb or uterus removed)
- ☐ Both ovaries removed
- ☐ Radiation or chemotherapy
- ☐ Strenuous exercise
- ☐ Illness
- ☐ Pregnancy
- ☐ Hormonal birth control (contraceptive pills, IUDs, injections, implants etc.)
- ☐ Breast feeding
- ☐ Other (*specify*)_______________________________
- ☐ Don't know

7. How old were you when your periods stopped?

- ☐ _____ years
- ☐ Don't Know

D2. Pregnancies

These questions ask about new pregnancies you may have had since **«D2 Date»**.

1. Since «D2_Date», have you been pregnant?

- ☐ Yes
- ☐ No → *go to Section D3*
- ☐ Don't know → *go to Section D3.*

2. Are you currently pregnant?

- ☐ Yes
- ☐ No
- ☐ Don't know

3. Since «D2_Date», how many pregnancies have you had? _____ pregnancies

4. For each pregnancy since «D2_Date», please fill in the column(s) below:

	PREGNANCY 1	PREGNANCY 2	PREGNANCY 3
How long was this pregnancy? *Mark ONE answer.*	☐ 3 months or less ☐ 4 to 6 months ☐ 7 months or more ☐ Don't know	☐ 3 months or less ☐ 4 to 6 months ☐ 7 months or more ☐ Don't know	☐ 3 months or less ☐ 4 to 6 months ☐ 7 months or more ☐ Don't know
What was the outcome of this pregnancy? *Mark 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 the remainder of this table only if the outcome was a live birth			
On what date was the baby/babies born?	____ / ____ / ________ mm dd yyyy	____ / ____ / ________ mm dd yyyy	____ / ____ / ________ mm dd yyyy
What was the sex of this baby/babies?	____ Number of Boys ____ Number of Girls	____ Number of Boys ____ Number of Girls	____ Number of Boys ____ Number of Girls
Did you breast feed this baby/babies? *Mark ONE answer.* **If Yes:** **For how many months did you breast feed this baby/babies?** *Mark ONE answer.*	☐ Yes ☐ No ☐ Don't know ☐ Less than 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 ☐ Less than 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 ☐ Less than 1 month ☐ 1 to 5 months ☐ 6 to 11 months ☐ 12 to 23 months ☐ 24 months or longer ☐ Don't know

D3. Birth Control and Menopausal Hormones

The next questions ask about birth control and hormone replacement therapy for menopausal symptoms.

1. **Since <u>«D3_1 Date»</u>, have you used birth control pills or other hormonal contraceptives (implants, IUD or injections)?**

   ☐ Yes
   ☐ No → *go to Question 5*
   ☐ Don't know → *go to Question 5.*

2. **Are you currently using birth control pills or other hormonal contraceptives?**

   ☐ Yes → *go to Question 4.*
   ☐ No

3. **How old were you when you last used birth control pills or other hormonal contraceptives?**

   ☐ ____ years
   ☐ Don't Know

4. **Since <u>«D3_4 Date»</u>, for how many months or years did you use birth control pills or other hormonal contraceptives in total?**

   ☐ ____ months OR ____ years
   ☐ Don't Know

The next questions are about hormone replacement therapy for menopausal symptoms.

5. **Since <u>«D3_5 Date»</u>, have you used estrogen, progesterone or other hormonal medications for menopausal symptoms, 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 Section E1*
   ☐ Don't know → *go to Section E1.*

6. **Were you still having periods when you first used hormonal replacement therapy?**

   ☐ Yes
   ☐ No
   ☐ Don't know

7. **Since <u>«D3_7 Date»</u>, for how many months or years have you used this hormone replacement therapy?**

   ☐ ____ months OR ____ years
   ☐ Don't Know

8. **What were the hormones you MAINLY used during that time?** *Mark ONE answer.*

   ☐ Estrogen only (e.g., Premarin, Estraderm, Progynova)
   ☐ Combined progesterone and estrogen, such as patches or tablets (e.g., Kliovance, Estalis Trisequens, Prempro)
   ☐ Combination of separate progesterone and estrogen, such as tablets, patches or IUDs (e.g., Mirena + Premarin, Provera + Progynova)
   ☐ Synthetic estrogen, progesterone and androgen (testosterone) (e.g., Tibolone, Livial, Xyvion)
   ☐ I only know brand name (specify) ____________________________________
   ☐ Other (specify)_______________________
   ☐ Don't know

9. **Are you currently using these hormones for menopausal symptoms?**

   ☐ Yes → *go to Section E1.*
   ☐ No

10. **How old were you when you last used these hormones for menopausal symptoms?**

    ☐ ____ years
    ☐ Don't Know

Section E

E1. Medications for Risk Reduction

The next questions are about medications for chemoprevention. Chemoprevention means taking a drug that reduces the chance of developing breast cancer.

1. **In the past 10 years, have you taken tamoxifen (Nolvadex, Soltamox), raloxifene (Evista), exemestane (Aromasin), anastrazole (Arimidex) or letrozole (Femara) to reduce the risk of developing breast cancer? Please do not include these medications if they were taken for treatment of your breast cancer.**

   - ☐ Yes
   - ☐ No → *go to Section E2*
   - ☐ Don't know → *go to Section E2.*

2. **Which medications have you taken?** *Mark ALL that apply.*

   - ☐ Nolvadex, Soltamox (tamoxifen)
   - ☐ Evista (raloxifene)
   - ☐ Aromasin (exemestane)
   - ☐ Arimidex (anastrazole)
   - ☐ Femara (letrozole)
   - ☐ Don't know

3. **How old were you when you first started using any of these medications to reduce your risk of developing breast cancer?**

   - ☐ _____ years
   - ☐ Don't Know

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

   - ☐ _____ months OR _____ years
   - ☐ Don't Know

5. **Are you currently taking any of these medications to reduce your risk of developing breast cancer?**

   - ☐ Yes → *go to Section E2*
   - ☐ No
   - ☐ Don't know → *go to Section E2.*

6. **At what age did you stop taking these medications?**

   - ☐ _____ years
   - ☐ Don't Know

E2. Other Medications

The next questions are about your regular use of certain medications. We are only interested in medications you took at least 2 times per week for 1 month or longer. Please complete the table below indicating how often and how long you took each of these medications.

	Have you **ever** used this medication at least 2 times per week for 1 month or longer?	During the **last 10 years,** have you taken this medication at least 2 times per week for 1 month or longer?	During the **last 10 years,** how long in total did you take this medication at least 2 times per week? (number of months or years)	During that period of use, **on average** how many times per week did you take this medication? (e.g., twice a day is 14 times per week)	Are you **currently** taking this medication at least 2 times per week?
Regular Strength Aspirin (Anacin, Bufferin, Excedrin etc.)	☐ Yes → ☐ No ☐ Don't know	☐ Yes → ☐ No ☐ Don't know	_____ ☐ months ☐ years	_____ times per week	☐ Yes ☐ No ☐ Don't know
Low-dose Aspirin (Baby Aspirin etc.)	☐ Yes → ☐ No ☐ Don't know	☐ Yes → ☐ No ☐ Don't know	_____ ☐ months ☐ years	_____ times per week	☐ Yes ☐ No ☐ Don't know
Acetaminophen (Tylenol, Anacin-3, Panadol, Aspirin Free Excedrin etc.)	☐ Yes → ☐ No ☐ Don't know	☐ Yes → ☐ No ☐ Don't know	_____ ☐ months ☐ years	_____ times per week	☐ Yes ☐ No ☐ Don't know
Non-steroidal anti-inflammatory medications such as ibuprofen, indomethacin, naproxen, mefenamic acid, or diclofenac (Advil, Aleve, Motrin, Nuprin, Idocin, Naprosy, Medipren etc.)	☐ Yes → ☐ No ☐ Don't know	☐ Yes → ☐ No ☐ Don't know	_____ ☐ months ☐ years	_____ times per week	☐ Yes ☐ No ☐ Don't know
Cox-2 inhibitors such as celecoxib, meloxicam, or etoricoxib (Celebrex, Vioxx, Bextra, Valdecoxib, Elecoxib, Celecoxib, Rofecoxib etc.)	☐ Yes → ☐ No ☐ Don't know	☐ Yes → ☐ No ☐ Don't know	_____ ☐ months ☐ years	_____ times per week	☐ Yes ☐ No ☐ Don't know

Section F

F1. Lifestyle; Alcohol

The next questions ask about your consumption of alcohol in the past 10 years.

1. In the past 10 years, did you drink alcohol for at least once per week for 6 months or longer?

☐ Yes
☐ No → *go to Section F2*
☐ Don't know → *go to Section F2.*

2. In the past 10 years, for how many years or months did you drink alcohol for at least once per week for 6 months or longer?

☐ _________ months **OR** _________ years
☐ Don't Know

3. When you consumed alcohol at least once per week, how much of each beverage did you usually drink? *For each beverage, mark only ONE answer.*

	None	Less than 1 per week	1-2 per week	3-4 per week	5-7 per week	8-14 per week	More than 14 per week	Don't Know
Beer (1 Drink = 1 bottle, can or glass)	☐	☐	☐	☐	☐	☐	☐	☐
Wine, Champagne (1 Drink = 1 glass)	☐	☐	☐	☐	☐	☐	☐	☐
Cocktails, Spirits (Liquor) (1 Drink = 1 cocktail, shot, or mixed drink*)*	☐	☐	☐	☐	☐	☐	☐	☐

4. Are you currently drinking alcohol at least once per week?

☐ Yes → *go to Section F2*
☐ No

5. At what age did you stop drinking alcohol at least once per week?

_____ years

F2. Lifestyle; Smoking

The next questions ask about cigarette smoking in the past 10 years.

1. In the past 10 years, have you smoked at least 1 cigarette per day for 3 months or longer?

- ☐ Yes
- ☐ No → *go to Section G*
- ☐ Don't know → *go to Section G.*

2. In the past last 10 years, for how many years or months did you smoke at least 1 cigarette per day?

- ☐ __________ years OR __________ months
- ☐ Don't Know

3. During the time you smoked at least 1 cigarette per day, how many cigarettes did you usually smoke in a day?

- ☐ _____ cigarettes per day
- ☐ Don't Know

4. Are you currently smoking at least 1 cigarette per day?

- ☐ Yes → *go to Section G.*
- ☐ No

5. At what age did you stop smoking at least 1 cigarette per day?

- ☐ _____ years
- ☐ Don't Know

Section G. Comments

Do you have any comments or additional information that you would like to tell us?

____

____

____

____

____

____

THANK YOU!

Thank you so much for taking the time to complete this questionnaire. We greatly appreciate your continued participation in the Breast Cancer Family Registry.