## The Sister Study Family Health Update Abbreviated - Version 1

$\square$

- Please use DARK BLUE OR BLACK BALLPOINT PEN.
- Mark only one answer for each question unless otherwise indicated.
- Follow the arrow from your response to find the next question.
- Only write comments in the spaces provided.
- Please keep this questionnaire clean, flat, and dry.
- Do not fold or tear any of the pages.

Fill in the bubbles COMPLETELY for each of the questions in this form.
Like this:
Not like this: $\varnothing \varnothing$

Your continued participation in the Sister Study is completely voluntary and greatly appreciated. All information you share will be kept confidential. If you are not comfortable answering a question, just skip it and go to the next one. If you do not know the answer to a question, please mark the bubble that says "Don't know."

- Please provide information for biological relatives only-that is those relatives related to you by blood, not by marriage or adoption.


## What is today's date?



MONTH


DAY


[^0]1. What is your mother's date of birth?


O Don't know
2. Is your mother still alive?


O No $\rightarrow$

4. How old was she when she died? |  |  |
| :--- | :--- |
| AGE |  | O Don't know

AND
5. What year did she die?


Don't know

| Was your mother ever diagnosed with... | NO | YES | When was your mother first diagnosed? If you are not sure, please give your best guess for her age. |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 6. breast cancer? | O No <br> No <br> Don't know GO TO 8 | O Yes |  |  | OR | BEST GUESS |
| 7. breast cancer in the other breast (at the same or a different time)? | ○ No <br> O Don't know | O Yes | OR <br> AGE |  | OR | BEST GUESS |
| 8. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | O No <br> O Don't know | - Yes | OR |  | OR | BEST GUESS |
| 9. pancreatic cancer? | O No <br> O Don't know | O Yes |  |  | OR | BEST GUESS |

## BIOLOGICAL SISTERS (DO NOT INCLUDE YOURSELF)

Next we would like to know about your sister(s). Please include only biological sisters with whom you share at least one parent. Let's start with your oldest (first-born) sister.

What is her first name?
SISTER \#1 $\square$
10. What is your oldest (first-born) sister's date of birth?
11. Is she your half or full sister?


O Full, share both parents

- Half, share mother
- Half, share father

12. Is this sister still alive?

| $\begin{array}{ll} \text { O Yes } & \rightarrow \\ \text { ONo } & \rightarrow \end{array}$ | 13. | What is this sister's age? |  | - Don't know |
| :---: | :---: | :---: | :---: | :---: |
|  | 14. | How old was she when she died? (If less than 1, write 00) <br> AND | $\begin{aligned} & \hline \text { AGE } \\ & \hline \end{aligned}$ | O Don't know |
|  |  | What year did she die? | YEAR | O Don't know |


20. Is/was this sister a twin, triplet, or other multiple?

- Yes, identical (monozygotic)

○ Yes, not identical (fraternal, dizygotic)
O Yes, don't know type

What is your next oldest (next born) sister's first name?
SISTER \#2

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

O I do not have any more biological sisters $\rightarrow$ GO TO QUESTION 76, PAGE 9
21. What is your next oldest (next born) sister's date of birth?


- Don't know

22. Is she your half or full sister?

O Full, share both parents

- Half, share mother
- Half, share father

23. Is this sister still alive?


| Was this sister ever diagnosed with... | NO | YES | When was this sister first diagnosed? If you are not sure, please give your best guess for her age. |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 27. breast cancer? | ○ No <br> - Don't know <br> GO TO 29 | O Yes |  |  | OR | BEST GUESS |
| 28. breast cancer in the other breast (at the same or a different time)? | ○ No <br> - Don't know | O Yes | OR |  | OR | BEST GUESS |
| 29. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | ○ No <br> O Don't know | - Yes | OR |  | OR | BEST GUESS |
| 30. pancreatic cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | - Yes |  |  | $\underline{\text { OR }}$ | BEST GUESS |

31. Is/was this sister a twin, triplet, or other multiple?

○ Yes, identical (monozygotic)
O Yes, not identical (fraternal, dizygotic)
O Yes, don't know type


O No

O I do not have any more biological sisters $\rightarrow$ GO TO QUESTION 76, PAGE 9
32. What is your next oldest (next born) sister's date of birth?


## Don't know

33. Is she your half or full sister?

O Full, share both parents

- Half, share mother
- Half, share father

34. Is this sister still alive?


| Was this sister ever diagnosed with... | NO | YES | When was this sister first diagnosed? If you are not sure, please give your best guess for her age. |  |
| :---: | :---: | :---: | :---: | :---: |
| 38. breast cancer? | ```O No O Don't know GO TO 40``` | O Yes |  | OR <br> AGE: <br> BEST GUESS |
| 39. breast cancer in the other breast (at the same or a different time)? | ○ No <br> ○ Don't know | O Yes | OR | OR <br> BEST GUESS |
| 40. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | ○ No <br> O Don't know | - Yes |  | OR <br> AGE: BEST GUESS |
| 41. pancreatic cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes | OR <br> AGE | OR $\square$ <br> AGE: <br> BEST GUESS |

42. Is/was this sister a twin, triplet, or other multiple?

○ Yes, identical (monozygotic)
O Yes, not identical (fraternal, dizygotic)
O Yes, don’t know type


O I do not have any more biological sisters $\rightarrow$ GO TO QUESTION 76, PAGE 9
43. What is your next oldest (next born) sister's date of birth?


Don't know
44. Is she your half or full sister?

O Full, share both parents

- Half, share mother
- Half, share father

45. Is this sister still alive?


46. Is/was this sister a twin, triplet, or other multiple?

○ Yes, identical (monozygotic)
O Yes, not identical (fraternal, dizygotic)
O Yes, don't know type

What is your next oldest (next born) sister's first name?
54. What is your next oldest (next born) sister's date of birth?
55. Is she your half or full sister?


YEAR
56. Is this sister still alive?


64. Is/was this sister a twin, triplet, or other multiple?

- Yes, identical (monozygotic)

○ Yes, not identical (fraternal, dizygotic)

- Yes, don't know type

O No

First name(s) of this sister's twin/multiples:


O I do not have any more biological sisters $\rightarrow$ GO TO QUESTION 76, NEXT PAGE
65. What is your next oldest (next born) sister's date of birth?


O Don't know
66. Is she your half or full sister?

O Full, share both parents

- Half, share mother
- Half, share father

67. Is this sister still alive?


| Was this sister ever diagnosed with... | NO | YES | When was this sister first diagnosed? If you are not sure, please give your best guess for her age. |  |
| :---: | :---: | :---: | :---: | :---: |
| 71. breast cancer? | O No <br> - Don't know <br> GO TO 73 | O Yes |  | OR <br> AGE: BEST GUESS |
| 72. breast cancer in the other breast (at the same or a different time)? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes |  | OR <br> BEST GUESS |
| 73. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | ○ No <br> ○ Don't know | O Yes | OR | OR <br> BEST GUESS |
| 74. pancreatic cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | - Yes |  | OR $\square$ <br> AGE: <br> BEST GUESS |

75. Is/was this sister a twin, triplet, or other multiple?

○ Yes, identical (monozygotic)
O Yes, not identical (fraternal, dizygotic)
O Yes, don’t know type

First name(s) of this sister's twin/multiples:


If you have more than 6 sisters, please answer the same questions for each sister and record your answers on a separate sheet of paper.

Next we would like to know about your daughter(s). Please include only biological daughters, not adopted or step-daughters. Let's start with your oldest (first-born) daughter.

O I do not have any biological daughters $\rightarrow$ GO TO QUESTION 106, PAGE 12
What is her first name?
DAUGHTER \#1 $\square$
76. What is your oldest (first-born) daughter's date of birth?


- Don't know

77. Is this daughter still alive?

| $\begin{array}{ll} \text { O Yes } & \rightarrow \\ \text { O No } & \rightarrow \end{array}$ |  | What is this daughter's age? |  | O Don't know |
| :---: | :---: | :---: | :---: | :---: |
|  | 79. | How old was she when she died? (If less than 1, write 00) AND |  | O Don't know |
|  | 80. | What year did she die? | $\frac{\underbrace{}_{\text {YEAR }}}{}$ | O Don't know |


| Was this daughter ever diagnosed with... | NO | YES | When was this daughter first diagnosed? If you are not sure, please give your best guess for her age. |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 81. breast cancer? | No <br> - Don't know GO TO 83 | O Yes |  |  | OR | BEST GUESS |
| 82. breast cancer in the other breast (at the same or a different time)? | ○ No <br> ○ Don't know | - Yes |  |  | OR | BEST GUESS |
| 83. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | ○ No <br> - Don't know | - Yes |  |  | OR | BEST GUESS |
| 84. pancreatic cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes |  |  | OR | BEST GUESS |

85. Is/was this daughter a twin, triplet, or other multiple?

- Yes, identical (monozygotic)

O Yes, not identical (fraternal, dizygotic)

- Yes, don't know type

First name(s) of this daughter's twin/multiples:


What is your next oldest (next born) daughter's first name?
DAUGHTER \#2 $\square$

O I do not have any more biological daughters $\rightarrow$ GO TO QUESTION 106, PAGE 12
86. What is your next oldest (next born) daughter's date of birth?


/


Don't know
87. Is this daughter still alive?


| Was this daughter ever diagnosed with... | NO | YES | When was this daughter first diagnosed? If you are not sure, please give your best guess for her age. |  |
| :---: | :---: | :---: | :---: | :---: |
| 91. breast cancer? | ```O No O Don't know GO TO 93``` | O Yes | OR <br> AGE | OR <br> BEST GUESS |
| 92. breast cancer in the other breast (at the same or a different time)? | O No <br> ○ Don't know | O Yes | OR <br> AGE | OR $\square$ <br> AGE: <br> BEST GUESS |
| 93. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | O No <br> ○ Don't know | O Yes |  | OR <br> AGE: BEST GUESS |
| 94. pancreatic cancer? | O No <br> ○ Don't know | O Yes | OR <br> AGE | OR $\square$ <br> AGE: BEST GUESS |

95. Is/was this daughter a twin, triplet, or other multiple?

○ Yes, identical (monozygotic)

- Yes, not identical (fraternal, dizygotic)

O Yes, don't know type

First name(s) of this daughter's twin/multiples:
 O No
$\square$

O I do not have any more biological daughters $\rightarrow$ GO TO QUESTION 106, NEXT PAGE
96. What is your next oldest (next born) daughter's date of birth?


Don't know
97. Is this daughter still alive?

| $\bigcirc$ Yes $\rightarrow$ |  | What is this daughter's age? |  | O Don't know |
| :---: | :---: | :---: | :---: | :---: |
| $\text { O No } \quad \rightarrow$ | $99 .$ | How old was she when she died? (If less than 1, write 00) AND |  | O Don't know |
| - Don't know | 100. | What year did she die? | YEAR | - Don't know |


| Was this daughter ever diagnosed with... | NO | YES | When was this daughter first diagnosed? If you are not sure, please give your best guess for her age. |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 101. breast cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \\ & \text { GO TO } 103 \end{aligned}$ | - Yes |  |  | OR | BEST GUESS |
| 102. breast cancer in the other breast (at the same or a different time)? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes | OR |  | OR | BEST GUESS |
| 103. ovarian cancer, fallopian tube cancer, or primary peritoneal cancer? | ○ No <br> O Don't know | - Yes | OR |  | OR | BEST GUESS |
| 104. pancreatic cancer? | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes |  |  | OR | BEST GUESS |

105. Is/was this daughter a twin, triplet, or other multiple?

- Yes, identical (monozygotic)
O Yes, not identical (fraternal, dizygotic)
O Yes, don’t know type $\square$
O No
If you have more than 3 daughters, please answer the same questions for each daughter and record your answers on a separate sheet of paper.


## BIOLOGICAL FATHER, BROTHERS, AND SONS

Next we would like to know about your biological father, brother(s), and son(s). Do not include relatives related to you through marriage or adoption.

| 106. <br> Have any of the following relatives been diagnosed with male BREAST CANCER? | NO | YES | When was he first DIAGNOSED? If you are not sure, please give your best guess. | What year was he BORN? |
| :---: | :---: | :---: | :---: | :---: |
| Father | O No <br> - Don't know | O Yes |  |  |
| Brother <br> O No biological brothers | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | O Yes | OR <br> Is he a full or half brother? Full, share both parents Half, share mother Half, share father |  |
| Brother | O No <br> ○ Don't know | - Yes | OR <br> Is he a full or half brother? Full, share both parents Half, share mother Half, share father |  |
| Son <br> - No biological sons | O No <br> - Don't know | O Yes |  |  |
| Son | $\begin{aligned} & \text { O No } \\ & \text { O Don't know } \end{aligned}$ | - Yes | OR |  |

If you have more brothers or sons who have been diagnosed with male BREAST CANCER, please answer the same questions for each one and record your answers on a separate sheet of paper.

## OTHER RELATIVES

Finally we would like to know about your other biological relatives. Do not include relatives related to you through marriage or adoption.
107. Have any of the following relatives been diagnosed with breast cancer? Mark all that apply.

On your mother's side:

- Mother's mother (your grandmother)

O Mother's father (your grandfather)
O Mother's sister (your aunt)

- Mother's brother (your uncle)

On your father's side:

- Father's mother (your grandmother)
- Father's father (your grandfather)
- Father's sister (your aunt)

O Father's brother (your uncle)

Children of siblings (Do not include children of spouse's siblings):

- Niece

O Nephew
108. Have you had BRCA1 genetic testing done?

O Yes
$\left.\begin{array}{l}\text { O No } \\ \text { O Don't know }\end{array}\right\}$ GO TO QUESTION 115, NEXT PAGE
109. What type of test was this?

O Search for any mutation (mutation search)
O Search for a known family mutation (direct or predictive test)

- Don't know

110. Were the results...

O Positive for BRCA1 (a mutation or rearrangement that increases risk)
O Negative for BRCA1 (no mutation or rearrangement that increases risk)
O Inconclusive result
O Don't know

- Prefer not to answer

111. How old were you when you had this test?


OR

112. Why did you have the test? Mark all that apply.


O I was diagnosed with breast cancer

- I was diagnosed with ovarian cancer

O Family member diagnosed with both breast and ovarian cancer
O Male family member diagnosed with breast cancer
O Ashkenazi Jewish heritage (usually Eastern European Jewish heritage)
o Close family member was tested for BRCA1 or BRCA2
○ Other, specify: $\square$
115. Have you had BRCA2 genetic testing done?

- Yes
$\left.\begin{array}{l}\text { O No } \\ \text { O Don't know }\end{array}\right\}$ GO TO QUESTION 122, NEXT PAGE

116. What type of test was this?

- Search for any mutation (mutation search)

O Search for a known family mutation (direct or predictive test)

- Don't know

117. Were the results...

O Positive for BRCA2 (a mutation or rearrangement that increases risk)
O Negative for BRCA2 (no mutation or rearrangement that increases risk)
O Inconclusive result
O Don't know

- Prefer not to answer

118. How old were you when you had this test?


OR

119. Why did you have the test? Mark all that apply.

O Same reason(s) as BRCA1 $\rightarrow$ GO TO QUESTION 122, NEXT PAGE
○ Family member diagnosed with breast cancer $\rightarrow$
120. What was his/her age when diagnosed?


Don't know

○ Family member diagnosed with ovarian cancer $\rightarrow$

O I was diagnosed with breast cancer

- I was diagnosed with ovarian cancer

O Family member diagnosed with both breast and ovarian cancer
O Male family member diagnosed with breast cancer
O Ashkenazi Jewish heritage (usually Eastern European Jewish heritage)
O Close family member was tested for BRCA1 or BRCA2

- Other, specify: $\square$

122. Have you had any genetic testing for breast, ovarian, or other cancer risk where multiple genes are tested at the same time (sometimes called genetic panels, cancer gene panels, hereditary cancer panels, or multigene testing)? Examples of multigene testing panels are listed below.
$\left.\begin{array}{l}\text { O Yes } \\ \text { O No } \\ \text { O Don't know }\end{array}\right\}$ GO TO QUESTION 126, NEXT PAGE
123. What was the name of the test? Mark all that apply.

O BreastNext (Ambry Genetics)

- OvaNext (Ambry Genetics)

O CancerNext (Ambry Genetics)

- BRCAPlus (Ambry Genetics)

O GYNPlus (Ambry Genetics)

- MyRisk (Myriad Genetics)

O OncoGeneDx Custom Panel (Gene Dx)
O OncoGeneDx High/Moderate Risk Panel (Gene Dx)

- Comprehensive Cancer Panel (Gene Dx)
- Breast/Ovarian Cancer Panel (Gene Dx)

O Breast Cancer High Risk Panel (Gene Dx)
O BRCAvantage Plus (Quest Diagnostics)

- PANEXIA (Myriad Genetics)
- BROCA (University of Washington)
- High Risk Hereditary Breast (Baylor)
- Breast and Ovarian (Baylor)
- High Risk Hereditary Breast (Invitae)
- Women's Hereditary Cancers (Invitae)
- Custom Panel (Invitae)
- Don't know panel name

O Other, specify: $\square$
124. Did you have positive results (a mutation or rearrangement that increases risk) for any of the genes in the multigene testing panels?

O Yes
○ No

- Don't know GO TO QUESTION 126, NEXT PAGE

125. For which genes did you have positive results (a mutation or rearrangement that increases risk)? Mark all that apply.

| O BRCA1 | ○ PALB2 <br> ○ BRCA2 |
| :--- | :--- |
| ○ CDH1 <br> O PTEN <br> ○ TP53 <br> ○ ATM |  |
| ○ PTK11 |  |
| ○ Other, specify: |  |

126. Have you been told that any of the following biological relatives have had testing done for BRCA1 or BRCA2: mother, father, full sister, full brother, daughter or son?
o Yes
O No
O Don't know
GO TO QUESTION 128
127. Did any of these blood relatives have a positive result for BRCA1 or BRCA2 (a mutation or rearrangement that increases risk)?

O Yes
O No
O Don't know
O Prefer not to answer
128. Have you been told that any of the following biological relatives have had other genetic testing done for breast or ovarian cancer: mother, father, full sister, full brother, daughter or son?
o Yes
○ No
○ Don't know GO TO QUESTION 130
129. Did any of these blood relatives have a positive result for other genetic testing for breast or ovarian cancer (a mutation or rearrangement that increases risk)?

O Yes
O No
O Don't know

- Prefer not to answer

130. Are you of Ashkenazi Jewish heritage? Persons of Ashkenazi Jewish heritage can usually trace their ancestry to Eastern Europe.

- Yes, mother's side
- Yes, father's side

O Yes, both parents
O No
O Don't know

- Prefer not to answer

Please check to see that all questions are answered.
Thank you for completing this questionnaire and for your continued participation in the Sister Study.
Please mail this form to us at the address below, using the postage-paid envelope we have provided.
The Sister Study, 4505 Emperor Blvd, Suite 400, Durham, NC 27703 phone: 1-877-4SISTER (1-877-474-7837); email: update@sisterstudy.org


[^0]:    We estimate the time to complete this questionnaire to be about 10 minutes. Please call us toll free at 877-4SISTER (877-474-7837) if you need help.

