

EDITORIAL NOTE: This extended family history questionnaire is in three sections. It is centered on the SUBJECT, who had a childhood cancer. In Section I, the father or mother of SUBJECT or another relative gives demographic information about SUBJECT and SUBJECT's siblings as well as a pregnancy history of SUBJECT or SUBJECT's spouse.

CHILDHOOD MEDULLOBLASTOMA STUDY
SECTION I. FAMILY HISTORY QUESTIONNAIRE

Confidential Information Not To Be Coded

IDENTIFICATION PAGE

SUBJECT ID NO. |_____|

[THIS PAGE TO BE REMOVED AFTER INTERVIEW IS COMPLETE]

SUBJECT NAME: _____

Address: _____

Social Security Number (SSN): _____

Phone Number: (_____) _____ - _____

MOTHER

FATHER

Name: _____

Name: _____

[RECORD ADDRESS AND PHONE NUMBER IF DIFFERENT FROM THE SUBJECT, OTHERWISE WRITE "SAME"]

[RECORD ADDRESS AND PHONE NUMBER IF DIFFERENT FROM THE SUBJECT, OTHERWISE WRITE "SAME"]

Address: _____

Address: _____

Work Phone: _____

Work Phone: _____

Home Phone: _____

Home Phone: _____

SSN: _____

SSN: _____

DEMOGRAPHICS

First I would like to ask you a few questions about (NAME)'s background and health.

1. What is (NAME)'s date of birth?

|_|_| - |_|_| - 19 |_|_|
MONTH DAY YEAR

2. Where was he/she born?

CITY/TOWN

STATE

OR

FOREIGN COUNTRY

3. Is (NAME) adopted?

Yes..... 1
No..... 2 (4)

- 3a. Was (NAME) adopted by a relative who knows the family history?

Yes..... 1
No..... 2 (BOX S1)

| |
|--|
| BOX S1 IF 3a = NO (2), THEN ASK QUESTIONS 4-8, 28-39 AND TERMINATE THE INTERVIEW |
|--|

4. Was (SUBJECT) a single or multiple birth?

SINGLE..... 1
MULTIPLE..... 2 (SPECIFY 1ST OF
(SPECIFY) _____ 2, ETC.)

5. Did (NAME) ever have any birth defects or genetic syndromes? (SPECIFY DETAILS)

YES..... 1
NO..... 2 (6)

IF YES, SPECIFY

5a. |_|_| _____

5b. |_|_| _____

5c. |_|_| _____

5d. |_|_| _____

6. How much did (SUBJECT) weigh at birth?

 |_|_| |_|_|
 LB OZ

7. What type of delivery did he have? SHOW CARD H

Normal, head first 1
Breech, bottom first 2
One foot first..... 3
One arm first 4
C-section 5

8. Which of the following, if any, were used during delivery? SHOW CARD I

Suction 1
Vacuum 2
Forceps 3
C-section 4
Other 5
None..... 6

SIBLINGS

Now I would like to ask you some questions about (NAME)'s full and half biological siblings, whether living or deceased, starting with the oldest. Please give me the first names of all (NAME)'s siblings. Please do not include adopted siblings.

WRITE THE FIRST NAME AND CIRCLE THE SEX OF EACH FULL OR HALF SIBLING AT TOP OF EACH COLUMN. ASK THE QUESTIONS FOR EACH SIBLING BEFORE GOING ON TO NEXT COLUMN. IF NONE, GO TO QUESTION 28.

| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|---|--|--|--|--|--|----|----|--|--|--|--|--|--|--|----|----|--|--|--|--|--|--|--|----|----|--|--|--|--|--|--|--|----|----|--|--|
| <p>9. (Starting with the oldest) CONFIRM: That's a sister? Or that's a brother?</p> <p>MALE1 FEMALE2</p> | <p>NAME</p> <p>_____</p> | <p>NAME</p> <p>_____</p> | <p>NAME</p> <p>_____</p> | <p>NAME</p> <p>_____</p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>10. What is (SIBLING)'s date of birth? CODE MONTH AND YEAR</p> | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">M</td> <td style="text-align: center;">Y</td> <td></td> <td></td> </tr> </table> | | | | | M | Y | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">M</td> <td style="text-align: center;">Y</td> <td></td> <td></td> </tr> </table> | | | | | M | Y | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">M</td> <td style="text-align: center;">Y</td> <td></td> <td></td> </tr> </table> | | | | | M | Y | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">M</td> <td style="text-align: center;">Y</td> <td></td> <td></td> </tr> </table> | | | | | M | Y | | |
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| M | Y | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| M | Y | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| M | Y | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>11. What is the relationship of this child to (NAME)? SHOW CARD G</p> <p>FULL SIBLING; SAME MOTHER, SAME FATHER1 HALF SIBLING; BY MOTHER2 HALF SIBLING; BY FATHER3</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>12. How much did (SIBLING) weigh at birth?</p> | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">LB</td> <td style="text-align: center;">OZ</td> <td></td> <td></td> </tr> </table> | | | | | LB | OZ | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">LB</td> <td style="text-align: center;">OZ</td> <td></td> <td></td> </tr> </table> | | | | | LB | OZ | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">LB</td> <td style="text-align: center;">OZ</td> <td></td> <td></td> </tr> </table> | | | | | LB | OZ | | | <table style="margin: auto;"> <tr> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> <td style="border: 1px solid black; width: 20px; height: 20px;"></td> </tr> <tr> <td style="text-align: center;">LB</td> <td style="text-align: center;">OZ</td> <td></td> <td></td> </tr> </table> | | | | | LB | OZ | | |
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| LB | OZ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LB | OZ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LB | OZ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LB | OZ | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| <p>13. What type of delivery did he/she have? SHOW CARD H</p> <p>NORMAL, HEAD FIRST1 BREECH, BOTTOM FIRST2 ONE FOOT FIRST3 ONE ARM FIRST4 C-SECTION5 (15) DON'T KNOW9</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> <p>.....4</p> <p>.....5 (15)</p> <p>.....9</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> <p>.....4</p> <p>.....5 (15)</p> <p>.....9</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> <p>.....4</p> <p>.....5 (15)</p> <p>.....9</p> | <p>.....1</p> <p>.....2</p> <p>.....3</p> <p>.....4</p> <p>.....5 (15)</p> <p>.....9</p> | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |

| | NAME | NAME | NAME | NAME |
|--|--|--|--|--|
| 14. Which of the following, if any, were used during delivery? SHOW CARD I | | | | |
| SUCTION |1 |1 |1 |1 |
| VACUUM..... |2 |2 |2 |2 |
| FORCEPS..... |3 |3 |3 |3 |
| C-SECTION..... |4 |4 |4 |4 |
| OTHER (SPECIFY)..... |5 |5 |5 |5 |
| NONE..... |6 |6 |6 |6 |
| DON'T KNOW |9 |9 |9 |9 |
| 15. Did (SIBLING) ever have any birth defects or malformations at birth? | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> NONE = 00 | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> NONE = 00 | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> NONE = 00 | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> NONE = 00 |
| NONE.....1 | _____ | _____ | _____ | _____ |
| YES (SPECIFY).....2 | _____ | _____ | _____ | _____ |
| 16. Did (SIBLING) have any illness during childhood requiring hospitalization for at least one night? | | | | |
| YES (SPECIFY)..... |1 |1 |1 |1 |
| NO |2 |2 |2 |2 |
| 17. Was (SIBLING) ever diagnosed as having cancer? | | | | |
| YES..... |1 |1 |1 |1 |
| NO |2 (21) |2 (21) |2 (21) |2 (21) |
| 18. Looking at SHOW CARD J on page S8, tell me what type of cancer did the physician state he/she had? | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> |
| 19. At what age was the cancer diagnosed? What year was that? | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> AGE IN YRS. 19 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> YEAR | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> AGE IN YRS. 19 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> YEAR | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> AGE IN YRS. 19 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> YEAR | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> AGE IN YRS. 19 <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> YEAR |
| 20. How was the child treated? Did he/she have: | | | | |
| a. surgery? | | | | |
| YES |1 |1 |1 |1 |
| NO |2 |2 |2 |2 |
| b. chemotherapy? | | | | |
| YES |1 |1 |1 |1 |
| NO |2 |2 |2 |2 |
| c. radiation? | | | | |
| YES |1 |1 |1 |1 |
| NO |2 |2 |2 |2 |

| | NAME | NAME | NAME | NAME |
|--|--|--|--|--|
| 21. Did (SIBLING) ever have a benign tumor? Yes.....1 No2 (25) |12 (25) |12 (25) | 1 2 (25) | 1 2 (25) |
| 22. Looking at SHOW CARD K, please tell me what kind of benign tumor it was. ADENOMAS COLORECTAL.....1 OVARIAN FIBROMA2 CARDIAC FIBROMA3 JAW CYSTS.....4 MENINGIOMA.....5 OTHER (SPECIFY)6 |123456 |123456 | 1 2 3 4 5 6 | 1 2 3 4 5 6 |
| 23. How old was (SIBLING) when the benign tumor was diagnosed? | AGE IN YRS. | AGE IN YRS. | AGE IN YRS. | AGE IN YRS. |
| 24. How was the tumor treated, by surgery or by observation only? Observation.....1 Surgery2 |12 |12 | 1 2 | 1 2 |
| 25. Is (SIBLING) still living? YES.....1 (NEXT SIB.) NO2 |1 (NEXT SIB.)2 | 1 (NEXT SIB.)2 | 1 (NEXT SIB.) 2 | 1 (NEXT SIB.) 2 |
| 26. In what year did he/she die? | 19 YEAR | 19 YEAR | 19 YEAR | 19 YEAR |
| 27. What was the cause of death? SHOW CARD L ON PAGE S8 GO TO NEXT SIBLING | | | | |

PREGNANCY HISTORY OF THE SUBJECT

This section asks about the pregnancies of the subject (those of female subjects and of the partners of male subjects).

28. Has (NAME) ever (been pregnant/fathered a pregnancy)?

YES..... 1
 NO 2 (NEXT SECTION
 DON'T KNOW 9 → RECORD END TIME)

29. How many times has (NAME) (been pregnant/fathered a pregnancy)?

|_|_|
 #

| | 1ST PREG. | 2ND PREG. | 3RD PREG. |
|---|-----------|-----------|-----------|
| 30. Beginning with the first pregnancy, please tell me the outcome of each one. SHOW CARD D CURRENTLY PREGNANT..... 0 BIRTH OF FULL-TERM CHILD 1 BIRTH OF PREMATURE CHILD 2 STILLBIRTH, AFTER 28 WEEKS OF PREGNANCY 3 MISCARRIAGE, BEFORE 28 WEEKS OF PREGNANCY 4 ELECTIVE ABORTION 5 ECTOPIC PREGNANCY (TUBAL PREGNANCY)..... 6 BABY WHO DIED SHORTLY AFTER BIRTH 7 UNKNOWN OUTCOME 9 | | | |
| ASK THE FOLLOWING QUESTIONS FOR ANY LIVE-BORN CHILDREN. 31. Is this child male or female? MALE 1 FEMALE 2 | | | |
| 32. What was the date of birth of this baby? _ _ - _ - _ _ _ _ - _ - _ _ _ _ - _ - _ _ MM DD YY MM DD YY MM DD YY | | | |
| 33. Was the child born with any birth defects? YES..... 1 NO 2 (35) DON'T KNOW 9 (35) | | | |

| | | | |
|--|---|---|---|
| 34. If yes, please specify. | a. _ _ _ _____ _____ | a. _ _ _ _____ _____ | a. _ _ _ _____ _____ |
| | b. _ _ _ _____ _____ | b. _ _ _ _____ _____ | b. _ _ _ _____ _____ |
| | c. _ _ _ _____ _____ | c. _ _ _ _____ _____ | c. _ _ _ _____ _____ |
| | d. _ _ _ _____ _____ | d. _ _ _ _____ _____ | d. _ _ _ _____ _____ |
| 35. Did the child ever have cancer? YES..... 1 NO 2 (38) DON'T KNOW 9 (38) | 1 2 (38) 9 (38) | 1 2 (38) 9 (38) | 1 2 (38) 9 (38) |
| 36. If yes, which type of cancer? SHOW CARD J ON PAGE S8 | _ _ | _ _ | _ _ |
| 37. In what year was this cancer diagnosed? [CODE AS YYYY] | _ _ _ YEAR | _ _ _ YEAR | _ _ _ YEAR |
| 38. Is the child still living? YES..... 1 (NEXT SEC.) NO 2 DON'T KNOW 9 (NEXT SEC.) | 1 (NEXT SEC.) 2 9 (NEXT SEC.) | 1 (NEXT SEC.) 2 9 (NEXT SEC.) | 1 (NEXT SEC.) 2 9 (NEXT SEC.) |
| 39. If no, please state the cause of death. SHOW CARD L ON PAGE S8 | _ _ | _ _ | _ _ |

This concludes this section.

SHOW CARD J: TYPE OF CANCER

- 1 Leukemia
- 2 Lung
- 3 Liver
- 4 Pancreas
- 5 Spleen
- 6 Breast
- 7 Ovaries
- 8 Prostate
- 9 Colon or digestive tract
- 10 Stomach
- 11 Skin
- 12 Brain
- 13 Other type of cancer, specify (do not code)
- 14 Not defined but widespread cancer of unknown type

SHOW CARD L: CAUSE OF DEATH

- 1 Cancer, specify type
- 2 Accident
- 3 Heart disease/attack
- 4 Stroke (clot of blood in brain)
- 5 Natural causes (old age)
- 6 Infection
- 7 Spina bifida-related complications
- 8 Renal failure
- 9 Other, specify