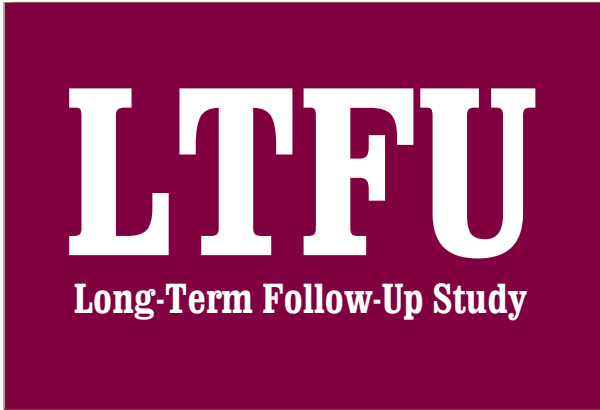




and

## UNIVERSITY OF MINNESOTA



*St. Jude Children's Research Hospital  
Children's Healthcare of Atlanta/Emory University  
Children's Hospital at Stanford  
Children's Hospital of Columbus  
Children's Hospital of Orange County  
Children's Hospital of Philadelphia  
Children's Hospital of Los Angeles  
Children's Hospital of Pittsburgh  
Children's Hospitals & Clinics of Minnesota,  
Minneapolis and St. Paul  
Children's Medical Center of Dallas  
Children's National Medical Center  
City of Hope National Medical Center  
Dana-Farber Cancer Institute  
Loma Linda University  
Mattel Children's Hospital at UCLA  
Mayo Clinic  
Memorial Sloan-Kettering Cancer Center  
Miller Children's Hospital  
Riley Hospital for Children - Indiana University  
Roswell Park Cancer Institute  
Seattle Children's Hospital  
St. Louis Children's Hospital  
Texas Children's Hospital  
The Denver Children's Hospital  
Toronto Hospital for Sick Children  
UAB/The Children's Hospital of Alabama  
University of California at San Francisco  
University of Michigan - Mott Children's Hospital  
University of Minnesota  
U.T.M.D. Anderson Cancer Center*

Thank you for participating in the Long-Term Follow-Up Study. Your participation continues to provide us with valuable information in the fight against childhood cancer and similar illnesses.

It has been about two years since we sent you our last general survey and we would like to update your information. Please fill out the following form that will bring us up-to-date on your health in the past two years. The length of time to complete varies between individuals, but generally requires 30-60 minutes.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

Self    Parent    Other: \_\_\_\_\_

Today's date:

/   /

**Our mailing address is:**  
Long-Term Follow-Up Study  
St. Jude Children's Research Hospital  
Department of Epidemiology  
Mail Stop 735  
262 Danny Thomas Place  
Memphis, TN 38105-3678

**Toll-free phone number:**  
1-800-775-2167

**e-mail:** LTFU@stjude.org

www.stjude.org/ltfu

Please! Do not mark below this line

Edit

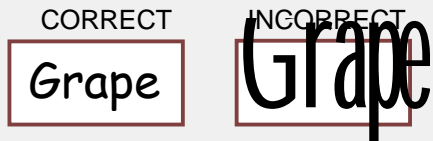
Survey #001   Code

2458454653

## INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:



### MARKING EXAMPLES

Below are some examples of how to fill out this questionnaire. Please look these over before you begin.

#### Example 1

1. During the past month, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

No     Yes

	Not sure		<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 0 auto;">If yes, age at first use</div> <p>years</p> <div style="border: 1px solid black; width: 40px; height: 30px; margin: 0 auto;"></div>
No	Yes		
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

#### Example 2

2. Have you ever taken. . .

- a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

- b. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES, such as Zocor, Pravachol, Lipitor, Colestid (colestipol), Tricor, Lescol, Lopid (gemfibrozil), Mevacor, niacin, or Lorelco-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

*MEVACOR*

	Not sure		<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 0 auto;">If yes, age at first use</div> <p>years</p> <div style="border: 1px solid black; width: 40px; height: 30px; margin: 0 auto; display: flex; justify-content: space-around;"> <span style="border: 1px solid black; padding: 2px 5px;">3</span> <span style="border: 1px solid black; padding: 2px 5px;">4</span> </div>
No	Yes		
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	

#### Example 3

3. When was this condition diagnosed?

04

Month (mm)

1995

Year (yyyy)

In the past we have asked you questions similar to those below. We would like to update this information.

A1. What is your current height without shoes?

--	--	--

Feet      Inches

A2. What is your current weight without shoes?

--	--	--

Pounds

A3. What is the highest grade or level of schooling you have now completed?

- 1-8 years (grade school)
- 9-12 years (high school) but did not graduate
- Completed high school/GED
- Training after high school, other than college
- Some college
- College graduate
- Post graduate level
- Other

*If Other, please describe.*

A4. What is your current employment status? Include unpaid work in the family business or farm. (Mark all that apply)

- Working full-time (30 or more hours per week)
- Working part-time (less than 30 hours per week)
- Caring for home or family (not seeking paid work)
- Unemployed and looking for work
- Unable to work due to illness or disability
- Retired
- Student
- Other

*If Other, please describe.*

If you are not currently working full or part time. . .

→ [Go to Question A6.](#)

A5. The following questions are about your present occupation. Please write your job title and brief details of what you do. If you have more than one job, please give the title of your main job:

A5a. Main job title:

A5b. Please briefly describe the primary tasks in your job:

A6. Over the last year, what was the total income of the household you live in?

- Less than \$20,000
- \$20,000 - \$39,999
- \$40,000 - \$59,999
- \$60,000 - \$79,999
- \$80,000 - \$99,999
- Over \$100,000
- Don't know

A7. During the past year, how many people in this household were supported on this income?

- |                            |                            |                                    |
|----------------------------|----------------------------|------------------------------------|
| <input type="checkbox"/> 1 | <input type="checkbox"/> 4 | <input type="checkbox"/> 7         |
| <input type="checkbox"/> 2 | <input type="checkbox"/> 5 | <input type="checkbox"/> 8         |
| <input type="checkbox"/> 3 | <input type="checkbox"/> 6 | <input type="checkbox"/> 9 or more |

A8. Over the last year, what was your personal income?

- None
- Less than \$20,000
- \$20,000 - \$39,999
- \$40,000 - \$59,999
- \$60,000 - \$79,999
- \$80,000 - \$99,999
- Over \$100,000

## MEDICAL CARE

The next questions are about health care received during the 2 year period between **November 2007 and November 2009**.

**B1. During this two year period, which of the following health care providers (excluding dentists) did you see or talk to for medical care? This includes routine and sick care. (Mark all that apply)**

- None **→ Go to Question B8, next page.**
- Physician (including Osteopath)
- Nurse Practitioner/Physician's Assistant
- Nurse
- Chiropractor
- Physical therapist
- Other

*If Other, please describe.*

**B2. Where did you receive your health care? (Mark all that apply)**

- Doctor's office
- Oncology (cancer) center or clinic
- Other type of clinic
- Hospital
- Emergency room or urgent care center
- Long-term follow-up clinic
- Other

*If Other, please describe.*

**B3. During this 2 year period, how many times did you see a physician?**

- None
- 1-2 times
- 3-4 times
- 5-6 times
- 7-10 times
- 11-20 times
- More than 20 times

**B4. As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the physician indicated in question B3 (during the 2 year period) were related to this previous illness?**

- None
- 1-2 visits
- 3-4 visits
- 5-6 visits
- 7-10 visits
- 11-20 visits
- More than 20 visits

**B5. Did you discuss any of the following issues with your physician or primary health care provider during any of these visits?**

	No	Yes
a. Heart disease . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
b. Osteoporosis (weak or brittle bones) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
c. Risk of developing cancer (breast, skin, other) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
d. Hepatitis C . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
e. Dental problems . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
f. Fertility issues . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
g. Mental health . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
h. Other issues related to your history of cancer or other serious illness during childhood . . . . .	<input type="checkbox"/>	<input type="checkbox"/>

*If Other issues, please describe.*

**B6. When was your MOST RECENT routine check-up where a doctor examined you and did tests to see if you had any health problems from your cancer or your cancer treatment?**

- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Never → Go to Question B8.

**B7. At this check-up did your doctor . . .**

	No	Yes
a. Give you advice about what to do to reduce risks . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
b. Discuss or order medical screening tests .	<input type="checkbox"/>	<input type="checkbox"/>
c. Suggest you see a cancer specialist . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
d. Suggest you see another type of medical subspecialist(s) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
e. Tell you that you had nothing to worry about based on findings at the check-up . .	<input type="checkbox"/>	<input type="checkbox"/>
f. Other . . . . .	<input type="checkbox"/>	<input type="checkbox"/>

*If yes to Other, please describe.*

**B8. When do you plan to have your NEXT visit with a doctor in order to examine you for any health problems from your cancer or your cancer treatment?**

- Less than 1 year from now
- 1-2 years from now
- 3-4 years from now
- 5 or more years from now
- Never

**B9. Do you currently have health insurance coverage?**

- Canadian resident
- No
- Yes

## MEDICAL SCREENING TESTS

The following questions are about medical screening tests you may have received.

When was the last time you had . . .

**C1. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or MUGA scan?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**C2. A test to measure your bone strength or bone mineral density (such as a DEXA or quantitative CT scan)?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**Continue on next page.**

**C3. A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood.**

**When was the last time that you had a blood stool test using a home kit?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**C4. Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems.**

**When was the last time you had either of these exams?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**MALES** → *Go to Question C8, next page.*

**FEMALES** ↓

**When was the last time you had . . .**

**C5. A mammogram?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**C6. A breast MRI?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

**C7. A pap smear (test for cancer of the cervix)?**

- Never
- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Don't know

*Continue on next page.*

**C8. Please indicate all medicines/drugs you took regularly during the two-year period between **November 2007 and November 2009.****

- We are only asking about medicines/drugs which you took consistently for more than one month, or for 30 days or more in a year.

- Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams.

- Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).

1. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

4. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

	Not sure			If yes, age at first use		If yes, are you currently taking?	
	No	Yes		years		No	Yes
1. BIRTH CONTROL PILLS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ESTROGENS OR PROGESTERONES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. TESTOSTERONES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. PILLS OR INSULIN FOR DIABETES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please! Do not mark below this line

**C8. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between **November 2007 and November 2009**.**

- We are only asking about medicines/drugs which you took consistently for more than one month, or for 30 days or more in a year.

- Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams.

- Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).

6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

10. OTHER PRESCRIBED DRUGS-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name **and** specify the reason the drug was prescribed.

	No	Yes	Not sure	If yes, age at first use	If yes, are you currently taking?
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years	No <input type="checkbox"/> Yes <input type="checkbox"/>
6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>
7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>
8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>
9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>
10. OTHER PRESCRIBED DRUGS-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> <input type="checkbox"/>

Please! Do not mark below this line



# Medical Conditions

The next series of questions relate to medical conditions that you have ever had. You may have previously told us about some of these conditions. We are asking again to make sure our records are current and to capture occurrences of new medical conditions.

Please indicate, by marking the box (either "No", "Yes", or "Not sure") if a doctor or other health care professional has told you that you have or have had any of the following conditions. If you answer "yes", please give your age when the condition first occurred. (If more than one occurrence, please give age at first occurrence.)

Because we need definite responses, it is very important to mark an answer for each question, even if you have never had that condition. **Please do not leave any questions blank (unmarked).**

## HEARING/VISION/SPEECH

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
D1. Hearing loss requiring a hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D2. Deafness in both ears not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D3. Deafness in only one ear not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D4. Tinnitus or ringing in the ears? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D5. Persistent dizziness or vertigo? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D6. Hearing loss, not requiring a hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D7. Any other hearing problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, describe this problem.**

D8. Legally blind in only one eye? . . . . .

**If yes, do you have any sight in this eye?**  
 No  Yes

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
D9. Legally blind in both eyes? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, do you have any sight?</b> <input type="checkbox"/> No <input type="checkbox"/> Yes					
D10. Cataracts? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D11. Glaucoma (excess pressure in the eyeball)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D12. Problems with double vision? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D13. A detached retina or any other condition of the retina? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, describe this problem.**

D14. Crossed or turned eyes (strabismus)? . . . . .

D15. Lazy eye (amblyopia)? . . . . .

D16. Any other trouble seeing with one or both eyes even when wearing glasses? . . . . .

D17. Very dry eyes requiring eye drops or ointment? . . . . .

D18. Any other eye problems? . . . . .

**If yes, describe this problem.**

Please! Do not mark below this line

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
D19. Stammering or stuttering? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D20. Any other speech defects? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe this defect.*

D21. Abnormal sense of taste? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D22. Loss of taste or smell lasting for 3 months or more? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

## URINARY SYSTEM

E1. Kidney stones? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E2. REPEATED (more than 3 in any 12 month period) kidney or bladder infections? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E3. Dialysis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E4. Blood in your urine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E5. Urinary incontinence? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E6. Any other kind of kidney, bladder or urinary tract disorder? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe this disorder.*

## HORMONAL SYSTEMS

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
F1. An overactive thyroid gland (hyperthyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F2. An underactive thyroid gland (hypothyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F3. Thyroid nodules? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F4. Swollen or enlarged thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F5. Diabetes that can be controlled with diet? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F6. Diabetes controlled with pills or tablets? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F7. Diabetes controlled with insulin shots? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F8. Deficiency of growth hormone? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F11. Have you ever broken a bone? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe all occurrences.*

F12. Any other hormonal problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
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*If yes, describe this problem.*

Males → Go to Question F17.

F13. FEMALES - Have you had a menstrual period naturally, that is, without needing hormones or medication?

No  Yes If yes, age at first occurrence:

If no, → Go to Question F15.

F14. FEMALES - At what age did you last have a menstrual period naturally, without needing hormones or medication?

years and   months old

F15. FEMALES - Which one of the following statements best describes you? (Select only one)

- a. I am having regular periods and I am not taking birth control pills or female hormones (example: Premarin, estrogen)
- b. I am having regular periods but I am using birth control pills to prevent a pregnancy
- c. My menstrual periods are irregular and I am taking birth control pills or female hormones to regulate my periods
- d. I am currently pregnant
- e. I am not having menstrual periods naturally but I am taking birth control pills or female hormones
- f. I am not having menstrual periods naturally and I am not taking birth control pills or female hormones
- g. Other

If Other, please describe.

If you selected a, b, c, or d → Go to Question G1.

If you selected e, f, or g → Go to Question F16.

F16. FEMALES - What caused your menstrual periods to stop? (Select only one)

- Normal or early menopause
- Surgery (example: a hysterectomy)
- Pregnancy
- Don't know
- Other

If Other, please describe.

Females → Go to Question G1.

F17. MALES -

LTFU Questionnaire on Men's Health

We are conducting an additional study funded by the Lance Armstrong Foundation to better understand fertility and sexual function in males. Participation would require 30-40 minutes. Because some of the questions are of a personal nature we would send you a separate questionnaire. Would you consider participating?

Yes  No  Not Sure

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

HEART AND CIRCULATORY SYSTEM

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

Yes, but the condition is no longer present | Yes, and the condition is still present | Not sure | If yes, age at first occurrence

G1. Congestive heart failure or cardiomyopathy (weak heart muscle)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
G2. A myocardial infarction (heart attack)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
G3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>
G4. Coronary heart disease? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>

If yes, describe this problem.

G5. Hypertension (high blood pressure) requiring medication? . . . . .

If yes, do you currently take hypertension medication?

No  Yes

Please! Do not mark below this line

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Have you ever been told by a doctor or other health care professional that you have, or have had . . .

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
G6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G7. Pericarditis or fluid around the heart? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G8. Pericardial constriction (scarring or tightness of the sac around the heart)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G9. Stiff or leaking heart valves? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G10. Blood clot in head, lung, arm, leg, or pelvis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
G12. High cholesterol (or triglyceride) requiring prescription medication? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<div style="border: 1px solid black; padding: 5px;"> <p><b>If yes, do you currently take medication for this?</b></p> <p><input type="checkbox"/> No   <input type="checkbox"/> Yes</p> </div>					
G13. Any other heart or circulatory problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

*If yes, describe this problem.*

G14. Has anyone in your immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?

No    Yes

## RESPIRATORY SYSTEM

Have you ever been told by a doctor or other health care professional that you have, or have had . . .

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
H1. Asthma? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H2. Chronic cough or shortness of breath for more than one month? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H3. Have you had a need for extra oxygen? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H4. Pneumonia, 3 or more times in the past 2 years? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H5. Emphysema? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H6. Lung fibrosis or "scarring" of the lung? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H7. Problems with breathing while at rest that lasted for more than 3 months? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
H8. Any other breathing or lung problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

*If yes, describe this problem.*

*Continue on next page.*

It is very important that you mark an answer for each of the following questions, even if you have never had that condition.

## DIGESTIVE SYSTEM

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
11. Hepatitis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, what type(s)? (Mark all that apply)</b>					
<input type="checkbox"/> Hepatitis A					
<input type="checkbox"/> Hepatitis B					
<input type="checkbox"/> Hepatitis C					
<input type="checkbox"/> Don't know					
<input type="checkbox"/> Other					
12. Cirrhosis of the liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
13. Any other liver trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, describe.</b>					
14. Intestinal (colon) polyps? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
15. Fatty liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
16. Esophageal strictures (narrowing of the esophagus)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
17. Rectal or anal fistula? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
18. Rectal or anal stricture (narrowing or scarring)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
19. Any other stomach or digestive trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

## SURGICAL PROCEDURES

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence years
J1. Amputation of an arm, leg, hand, foot? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, specify (example: left hand, right foot).</b>				
J2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
J3. Other surgery of spinal cord or spine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, specify.</b>				
J4. Leg lengthening or shortening procedures? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
J5. Joint replacement? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, specify.</b>				
J6. Other bone surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, specify.</b>				
J7. Coronary artery bypass surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
J8. Pericardiectomy (stripping of the sac around the heart)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

Please! Do not mark below this line

It is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence years
J9. Heart catheterization ("heart cath")? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J10. Angioplasty (enlarging a heart vessel using a balloon)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J11. Surgery for heart valve replacement? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J12. Surgery for pacemaker? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J13. Other heart surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, specify.*

J14. Surgery for intestinal obstruction (blocked intestines)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J15. Colostomy or ileostomy (stool going into a bag)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J16. Biopsy or removal of lump in thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J17. Removal of part or all of the thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J18. Removal of the spleen? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J19. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J20. Breast biopsy? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J21. Breast-conserving or breast-sparing surgery (lumpectomy)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J22. Mastectomy or removal of a breast? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, was one or both breasts removed?**  
 One    Both

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence years
J23. Any lung surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<i>If yes, specify.</i>				
J24. Periodontal (gum) surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J25. Heart transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J26. Lung transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J27. Kidney transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J28. Liver transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J29. Bone marrow transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J30. Other organ transplant? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, specify transplant.*

J31. Cataract surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>Males → Go to Question J35.</b>				
J32. Removal of one ovary? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J33. Removal of both ovaries? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J34. Removal of uterus? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>Females → Go to Question J37.</b>				
J35. Removal of one testis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J36. Removal of both testes? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J37. Any other surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, specify surgery.*

Please! Do not mark below this line

Just a reminder - it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

## BRAIN AND NERVOUS SYSTEM

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

K1. Problems with learning or memory? . . . . .

	No			Not sure	
	□	□	□	□	□

If yes, age at first occurrence  
years

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**If yes and still present**, please rate the severity of these problems:

- Mild**; does not interfere with my work, school, or general life. I did not need special help in school.
- Moderate**; interferes with my work, school, or general life, but I am capable of independent living. I used special help in school.
- Severe**; I am significantly impaired in my school or work performance or in my general life.
- Disabling**; I am unable to perform daily activities such as taking care of myself; I require full-time help or I am living in an institution for people with disabling conditions.

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No			Not sure	
	□	□	□	□	□

If yes, age at first occurrence  
years

--	--

K2. Epilepsy, repeated seizures, convulsions, or blackouts? . . .

**If yes, describe this problem and list medications.**

**If yes**, are you currently taking medication for this?

No     Yes

K3. Migraine? . . . . .

	No			Not sure	
	□	□	□	□	□

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K4. Other severe headaches? . . .

	No			Not sure	
	□	□	□	□	□

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**If yes, list medications if required to control.**

Continue on next page.

**Just a reminder - it is very important that you mark an answer for each of the following questions, even if you have never had that condition.**

**Have you ever been told by a doctor or other health care professional that you have, or have had. . .**

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
K5. Problems with balance, equilibrium, or ability to reach for or manipulate objects? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<p><b>If yes and still present, please rate the severity of these problems:</b></p> <p><input type="checkbox"/> <u>Mild</u>; does not affect walking or my daily routine.</p> <p><input type="checkbox"/> <u>Moderate</u>; it is bothersome and affects my walking but I am able to do my daily routine.</p> <p><input type="checkbox"/> <u>Severe</u>; this problem significantly affects my walking and my daily routine.</p> <p><input type="checkbox"/> <u>Disabling</u>; I require a wheelchair or cannot walk because of this problem.</p>					
K6. Tremors or problems with movements? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K7. Problems chewing or swallowing solids or liquids? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K8. Decreased sense of touch or feeling in hands, fingers, arms or legs? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K9. Prolonged pain in arms, legs or back? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K10. Abnormal sensation in arms, legs or back? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K11. Weakness or inability to move arm(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K12. Weakness or inability to move leg(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K13. Paralysis of any kind? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**Have you ever been told by a doctor or other health care professional that you have, or have had. . .**

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
K14. Have you had a stroke? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, as a result of the stroke . . .</b>					
a. Did the symptoms last more than 24 hours?	<input type="checkbox"/> No <input type="checkbox"/> Yes				
b. Did it affect:					
Speech. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Only one side of the body . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Both sides of the body . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c. Did you lose consciousness?	<input type="checkbox"/> No <input type="checkbox"/> Yes				
d. Did you have weakness or inability to move arm(s)? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
e. Did you have weakness or inability to move leg(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
f. Did you have paralysis of any kind? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, describe this problem.</b>					
K15. Any other brain or nervous system problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, describe this problem.</b>					

Please! Do not mark below this line



Questions L1 to L18 relate to the past 7 days.

Below is a list of problems people sometimes have. Please read each one carefully and mark the box that best describes how much that problem has distressed or bothered you during the past 7 days including today.

Mark only one answer for each problem and try not to skip any items.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
L1. Nervousness or shaking inside. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L2. Faintness or dizziness. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L3. Pains in heart or chest. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L4. Thoughts of ending your life . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L5. Suddenly scared for no reason. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L6. Feeling lonely. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L7. Feeling blue. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L8. Feeling no interest in things . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L9. Feeling fearful . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L10. Nausea or upset stomach. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L11. Trouble getting your breath. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L12. Numbness or tingling in parts of your body. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L13. Feeling hopeless about the future. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L14. Feeling weak in parts of your body . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L15. Feeling tense or keyed up. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L16. Spells of terror or panic. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L17. Feeling so restless you couldn't sit still. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L18. Feelings of worthlessness. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

L19. In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

L20. Do you currently have anxieties/fears as a result of your cancer, leukemia, tumor or similar illness, or its treatment?

- No anxiety/fears
- Small amount of anxiety/fears
- Medium amount of anxiety/fears
- A lot of anxiety/fears
- Very many, extreme anxiety/fears

L21. How much bodily pain have you had during the past 4 weeks?

- None → Go to Question M1, next page.
- Very mild
- Mild
- Moderate
- Severe
- Very severe

L22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all                       Quite a bit
- A little bit                       Extremely
- Moderately

L23. For pain that you have had during the past 4 weeks, where has this pain been located? (Check all that apply)

- Head                               Abdomen
- Neck                               Back
- Chest                               Pelvis
- Hands/Arms                       Legs/Feet
- Other

**Specify**

Please! Do not mark below this line

## MARITAL STATUS

**M1. What is your current living arrangement?**  
(Mark all that apply)

- Live with spouse/partner
- Live with parent(s)
- Live with roommate(s)
- Live with brother(s) and/or sister(s)
- Live with other relative(s) (not including minor children)
- Live alone
- Other

Specify

**M2. Which of the following best describes your current marital status?**

- Single, never married or never lived with partner as married **→ Go to Question N1.**
- Married
- Living with partner as married
- Widowed
- Divorced
- Separated or no longer living as married

**M3. How many times have you been married or lived as married?**

- |                          |                          |                          |                          |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1                        | 2                        | 3                        | 4                        | 5                        | 6                        | 7                        | 8                        | 9+                       |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## HEALTH HABITS

### Alcohol

**N1. In your entire life, have you ever had at least 2 drinks of any kind of alcoholic beverage?**

- No **→ Go to Question N7, next page.**
- Yes

**N2. How old were you when you first started drinking alcohol?**

--	--

 years old

**N3. During the last 12 months, how many alcoholic drinks did you have on a typical day when you drank alcohol? (If less than one per day, enter 0.)**

Wine (4 oz. glass):	Beer (12 oz. can):	Mixed drink (1 shot):						
<table border="1"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>			<table border="1"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>			<table border="1"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table>		
Glasses a day	Cans a day	Drinks a day						

**N4. During the last 12 months, what is the largest number of drinks you had on any single day? Was it...**

- 24+ drinks
- 12-23 drinks
- 8-11 drinks
- 5-7 drinks
- 4 drinks
- 3 drinks
- 2 drinks
- 1 drink

**N5. During the last 12 months, how often did you usually have any kind of drink containing alcohol?**

- Every day
- 5 to 6 times a week
- 3 to 4 times a week
- twice a week
- once a week
- 2 to 3 times a month
- once a month
- 3 to 11 times in the past year
- 1 or 2 times in the past year
- Never in the past year

**N6. During the last 12 months, how often did you have 5 or more (males) or 4 or more (females) drinks containing any kind of alcohol in a single day?**

- Every day
- 5 to 6 days a week
- 3 to 4 days a week
- two days a week
- one day a week
- 2 to 3 days a month
- one day a month
- 3 to 11 days in the past year
- 1 or 2 days in the past year
- Never in the past year

**Smoking**

**N7. Have you smoked at least 100 cigarettes in the previous two years?**

- No → Go to Question N13.
- Yes └

**N8. If you started smoking since you last provided us this information on %fu2date%, how old were you when you started smoking?**

--	--

**N9. Do you smoke cigarettes now?**

- No
- Yes

**N10. On average, how many cigarettes a day do/did you smoke?**

--	--

**N11. How many years, in total, have you smoked?**

--	--

**N12. If you currently smoke, how many times in the past 12 months have you tried to quit smoking and not smoked for at least 24 hours?**

--	--

**N13. In the past year, have you ever used any of these tobacco products? (Mark all that apply)**

		Never used	No longer use	Occasionally use	Regularly use
Chewing tobacco . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snuff tobacco. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pipes. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cigars. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**N14. For any of those that you have used or are currently using, how long have you used it?**

		Less than 1 year	1 - 2 years	3 - 4 years	5 - 10 years	11+ years
Chewing tobacco . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snuff tobacco . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pipes. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cigars . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Physical Activity

The following questions are about exercise, recreation, or physical activities other than your regular job duties.

N15. During the past month, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

- No  
 Yes

We are interested in two types of physical activity: vigorous and moderate.

- Vigorous activities cause large increases in breathing or heart rate.
- Moderate activities cause small increases in breathing or heart rate.

N16. Now thinking about the vigorous physical activities you do in a usual week, do you do vigorous activities for at least 10 minutes at a time, such as running, aerobics, wheelchair basketball, heavy yard work, or anything else that causes large increases in breathing or heart rate?

- No **→ Go to Question N19.**  
 Yes

N17. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

Days per week

N18. On days when you do vigorous activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

Minutes per day

N19. Now, thinking about the moderate physical activities you do in a usual week, do you do moderate activities for at least 10 minutes at a time, such as brisk walking, bicycling, gardening, manual operation of a wheelchair, or anything else that causes small increases in breathing or heart rate?

- No **→ Go to Question N22.**  
 Yes ↓

N20. How many days per week do you do these moderate activities for at least 10 minutes at a time?

Days per week

N21. On days when you do moderate activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

Minutes per day

N22. Because of any impairment or health problems, do you need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around your home?

- No  
 Yes

N23. Because of any impairment or health problems, do you need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- No  
 Yes

N24. Does any impairment or health problem keep you from holding a job or attending school?

- No  
 Yes

N25. Do you currently have a driver's license?

- No  
 Yes

**N26. Over the last 2 years, how long (if at all) has your health limited you in each of the following activities?**

(Mark one box for each item.)	Not limited at all		
	Limited for 3 months or less	Limited for more than 3 months	
a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Walking uphill or climbing a few flights of stairs. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bending, lifting, or stooping . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Walking one block . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Eating, dressing, bathing, or using the toilet . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**OTHER ISSUES**

**Please rate how concerned you are about the following:**

	Not at all concerned				
	Not very concerned			Concerned	
	Somewhat concerned		Very concerned		
	Very concerned				
O1. Your future health . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O2. Your ability to have children . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O3. Developing a cancer . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O4. Your ability to get health insurance. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O5. Your ability to get life insurance . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O6. Any other issues . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please specify.*

**CANCER, LEUKEMIA, OR TUMOR**

**P1. Have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse) since you last provided us information in %LastMo%, %LastYr%? (Please include skin cancers.)**

No **→ Go to next page.**

Yes **↓**

What was the name of this disease?

If this was a skin cancer, where was it located on your body? (Example: right upper arm, left ear)

Where was this diagnosed?

Doctor's name
Hospital or clinic
Address
City, State, Zipcode

Was this a:

- Recurrence of original diagnosis
- New cancer, leukemia, tumor, or similar illness
- Don't know

**Date of Recurrence or New Diagnosis:**

Month (mm)		Year (yyyy)			

**Please use a separate sheet of paper for additional cancers**

## **FAMILY HISTORY INFORMATION**

Conditions or illnesses occurring in family members may be important clues in determining our genetic make-up. The following section of the questionnaire deals with cancer, conditions present at birth, and hereditary conditions that may be present in your children. Please use the list below to complete the following section.

### **Cancer**

***Any diagnosis of cancer or malignant tumor, such as:***

Leukemia	Wilms tumor
Retinoblastoma	Lymphoma
Brain tumor	Teratoma
Hodgkins disease	Seminoma
Sarcoma	Neuroblastoma
Germ cell tumor	Carcinoma
Cancer - any other type, or location unknown	
Skin cancer - Please note if melanoma or non-melanoma	

### **Conditions Present at Birth**

***Any abnormality present at birth, such as:***

Blindness or difficulty seeing	Hole in the heart
Crossed eyes (strabismus)	Other congenital heart defect
Eyes different colors	Down Syndrome Trisomy 21
Hare lip (cleft lip)	Open spine (spina bifida)
Hole in roof of mouth (cleft palate)	Exposed brain (anencephaly)
Absent, fused or extra fingers or toes	Large or multiple birth marks
Hip displacement	Water on the brain (hydrocephalus)
Diverted urinary stream (hypospadias)	Macrocephaly (enlarged head)
Undescended testicle (cryptorchism)	Microcephaly (small head)
Deafness or impaired hearing	Hemihypertrophy (enlargement of one arm or leg)
Shortened limbs	Deformed chest
Club foot	Other skeletal abnormality

### **Hereditary Conditions**

***Some of the more common conditions known to be hereditary:***


Achondroplasia	Multiple exostoses
Acrocephalosyndactyly	Multiple polyposis
Aniridia (missing an iris)	Myotonic dystrophy
Apert's syndrome	Neurofibromatosis (type 1)
Ataxia-telangiectasia	Nevoid basal cell carcinoma syndrome
Beckwith-Wiedemann syndrome	Osteogenesis imperfecta
Bilateral acoustic neurofibromatosis (type 2)	Polycystic disease of the kidney
Bloom's syndrome	Polyposis coli (Gardner's syndrome)
Congenital megacolon (Hirschsprung's disease)	Tuberous sclerosis
Cystic fibrosis	Turner's syndrome
Fanconi's anemia	Von Hippel-Lindau syndrome
Klinefelter's syndrome	Von Recklinghausen's disease
Marfan's syndrome	Wiskott-Aldrich syndrome
	Xeroderma pigmentosum

Please! Do not mark below this line

# PREGNANCY AND OFFSPRING

Q1. Have you, or your partner, had any new pregnancies since you last provided us with this information on %fu2date%?

No → Go to Question R1 on page 25.

Yes 

Q2. Are you, or your partner, currently pregnant?

No  
 Yes

Q3. Please write down the names of each of your children who have been born since %fu2date%. Indicate whether each child has a history of cancer, a birth defect, and/or any hereditary conditions (refer to the list of conditions on the previous page). Please list twin births or multiple births as separate children. **Use a separate piece of paper if you need to record more pregnancies.**

Full Name (First, Middle, Last)	Sex	Date of Birth (Mo/Day/Yr)	Status	Date of Death (Mo/Day/Yr)	Medical history of cancer, birth defect, hereditary condition Provide specific type.	Age of onset (yrs)
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead			
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead			
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead			
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead			

Q4. This question concerns the birth (biological) parents of your children listed above. Please list the other parent or parents of your children. **Use a separate sheet of paper if you need to record additional parents.**

Full Name of other parent (First, Middle, Last)	Date of Birth (Mo/Day/Yr)	Status	Date of Death (Mo/Day/Yr)	Medical history of cancer, birth defect, hereditary condition Provide specific type.	Age of onset (yrs)
		<input type="checkbox"/> Alive <input type="checkbox"/> Dead			

Please list the names of the biological children of this parent.

**Q5. Since %fu2date%, please fill in the following information for each of your pregnancies, or each time a woman has become pregnant by you, regardless of the outcome.**

**Pregnancy outcome**

	Live birth	Stillbirth	Miscarriage	Medical abortion	Your age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
Pregnancy 1. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 2. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 3. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 4. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 5. ....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**Please attach a separate sheet of paper, if more than 5 pregnancies**

*Continue on next page.*



## OTHER TREATMENT

We are interested in whether you have had any radiation or chemotherapy for cancer or similar illness. Radiation is a treatment you would have received in a radiation therapy department and does not include CAT scans, MRI's, or diagnostic x-rays.

R1. Have you received any radiation treatment since %fu1date%?

- No → *Go to Question R2.*
- Yes
- Not sure

If yes, please indicate the date of any (additional) radiation treatment you received for a recurrence or a new cancer.

Date of Treatment

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month (mm)		Year (yyyy)			

Please indicate the reason for radiation.

Where was the radiation performed?

Hospital or clinic
Address
City, State, Zipcode
Doctor's name

R2. Have you received any chemotherapy treatment since %fu1date%?

- No → *Go to next page.*
- Yes
- Not sure

If yes, please indicate the date of any (additional) chemotherapy treatment you received for a recurrence or a new cancer.

Date of Treatment

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Month (mm)		Year (yyyy)			

Please indicate the reason for chemotherapy.

Where was the chemotherapy performed?

Hospital or clinic
Address
City, State, Zipcode
Doctor's name

*Continue on next page.*

This form is a medical release that we would like you to sign. It will give us permission to obtain copies of parts of your medical records that we may need to review, such as treatment history for your cancer or similar illness, or pathology reports for a subsequent cancer. You may have already signed a similar release when you filled out a previous questionnaire; however, since that release may have expired we need to ensure that your permission is kept current.

## LONG-TERM FOLLOW-UP STUDY

### HIPAA<sup>1</sup> AUTHORIZATION TO USE AND DISCLOSE INDIVIDUAL HEALTH INFORMATION FOR RESEARCH

- 1. Purpose.** As a research participant, I authorize Leslie L. Robison, Ph.D. and the researcher's staff to use and disclose my individual health information for the purpose of conducting the research project entitled Long-Term Follow-Up (LTFU) Study.
- 2. Individual Health Information to be Used or Disclosed.** My individual health information that may be used or disclosed to conduct this research includes medical records since the diagnosis of a serious illness such as a cardiac condition or a cancer or similar illness.
- 3. Parties Who May Disclose My Individual Health Information.** The researcher and the researcher's staff may obtain my individual health information from:
- Hospitals: \_\_\_\_\_  
Clinics: \_\_\_\_\_  
Other Providers: \_\_\_\_\_  
Health Plan: \_\_\_\_\_  
and from hospitals, clinics, health care providers and health plans that provide my health care during the study.
- 4. Parties Who May Receive or Use My Individual Health Information.** The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Leslie L. Robison, Ph.D., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Molecular Center (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), and the LTFU Statistical Center (Seattle, WA).
- 5. Right to Refuse to Sign this Authorization.** I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
- 6. Right to Revoke.** I can change my mind and withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Mail Stop 735, Memphis, TN 38105 to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for this research study. No further health information about me will be collected by or disclosed to the researcher for this study.
- 7. Potential for Re-disclosure.** Once my health information is disclosed under this authorization, there is a potential that it will be re-disclosed outside this study and no longer covered by this authorization. However, the research team and the St. Jude Institutional Review Board (the committee that reviews studies to be sure that the rights and safety of study participants are protected) are very careful to protect your privacy and limit the disclosure of identifying information about you.

**7A.** Also, there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I will receive a copy of this authorization form after it is signed.



\_\_\_\_\_  
Printed name of research participant

\_\_\_\_\_  
Date of birth

\_\_\_\_\_  
Signature of research participant or research  
Participant's personal representative

\_\_\_\_\_  
Today's Date



\_\_\_\_\_  
Printed name of research participant's personal representative

\_\_\_\_\_  
Description of personal representative's authority to act on behalf of the research participant

<sup>1</sup> HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

**Please! Do not mark below this line**

**We have your current address and phone as:**

**Is this information correct, or are you planning on moving in the next 6 months?**

Correct    Not correct    Moving

If this information is not correct, please give us your correct address or location:

Address	
City	State
Zip Code	Phone Number

Please provide the name and address of someone who could give us your new address should you move. We will contact this person only if we are unable to reach you at your home address.

Name	
Address	Relationship to you
City	State
Zip Code	Phone Number

Do you have an email address we could use to contact you?

No    Yes   **→**

Your Email Address

On average, how many times per week do you use the internet?

Never    1-10 times    11 or more times

---

**Please! Do not mark below this line**

**We are always interested in your input in the follow-up study.  
Use this space for any additional comments you may have:**

**When you have completed this questionnaire please return it to us in the enclosed envelope.**

**Mail to:**

**LONG-TERM FOLLOW-UP STUDY**  
St. Jude Children's Research Hospital  
Department of Epidemiology  
Mail Stop 735  
262 Danny Thomas Place  
Memphis, TN 38105-3678

**Thank you!**