LTFU
Long-Term Follow-Up Study

St. Jude Children's Research Hospital

More Knowledge = More Power

Thank you for participating in the LTFU Study. This study has been a powerful resource for over 25 years. Your responses become even more vital with each year of follow-up. It's important for us to know if things have changed, and just as important to know if they stayed the same!

Introducing myLTFU!

We recently launched a new online study portal called myLTFU. This is a convenient source for important study updates, surveys, resources, and activities. This survey is currently available in your myLTFU portal. You can complete the questions anywhere, on any device. You can also pause and return whenever you want. Please consider activating your account now.

You can learn more about myLTFU by going to this website: **ltfu.stjude.org/myltfu**

Your my LTFU keycode is:

Choose the most convenient option to complete your survey.

Computer, tablet, or smartphone

Visit **ltfu.stjude.org/myltfu** to get started

It's not too late. If you choose to complete this survey online then you will be entered in a drawing to win a ***smart watch!***

Print

Just fill out this survey and **mail it back** to us in the postage- paid envelope.

Phone

If you would like to answer the survey questions over the phone, or schedule a convenient time to speak with one of our trained interviewers, please **contact us:**

- Call toll free at **1-800-775-2167**
- Email **LTFU@stjude.org**

Please! Do not mark below this line

Edit | Survey # | Code

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Thank you!

As a small token of our appreciation, we will send you a $10 Amazon gift code after we receive your completed survey. Some participants have mentioned that they do not want the gift code because they want to donate it to the study. Please check the box below if you *do not* want a gift code. Otherwise, it is our pleasure to send you this as a "thank you."

PLEASE START YOUR SURVEY HERE

☐ Please donate my $10 gift to the LTFU Study *(optional)*

Today's date:

☐☐ / ☐☐ / ☐☐☐☐

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The questions in this survey relate to:

Person completing this survey is:

Your relationship:

☐ Self ☐ Parent ☐ Other: _____

If you are completing the survey on the participant's behalf, be aware that all survey questions are about

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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. Since this time last year, have you lost more than 10 pounds unintentionally (not due to dieting or exercise)?

☐ Yes ☐ No ☐ Not sure

A4. Are you of Hispanic, Latino, or Spanish origin?

☐ No, not of Hispanic, Latino, or Spanish origin
☐ Yes, Mexican, Mexican American, Chicano
☐ Yes, Puerto Rican
☐ Yes, Cuban
☐ Yes, another Hispanic, Latino, or Spanish origin

A5. What is your race? (Mark one or more boxes)

☐ White
☐ Black, African American
☐ American Indian or Alaska Native
☐ Asian Indian
☐ Chinese
☐ Filipino
☐ Japanese
☐ Korean
☐ Vietnamese
☐ Other Asian, specify:_____
☐ Pacific Islander
☐ Some other race, specify:_____

_____

A6. 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.

A7. What is your current employment status? Include unpaid work in the family business or farm. (Check 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 A9, next page.**

A8. 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.

a. Main job title:

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

Please! Do not mark below this line

A9. What is your current living arrangement? (Check 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

A10. Which of the following best describes your current marital status?

- ☐ Single, never married or never lived with partner as married → **Go to Question A12.**
- ☐ Married
- ☐ Living with partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

A11. How many times have you been married or lived as married?

1	2	3	4	5	6	7	8	9+
☐	☐	☐	☐	☐	☐	☐	☐	☐

A12. What sex were you assigned at birth, on your original birth certificate?

- ☐ Male
- ☐ Female

A13. How do you describe yourself? (Check one)

- ☐ Male
- ☐ Female
- ☐ Transgender
- ☐ Do not identify as male, female, or transgender

A14. How many people currently live in your household (including you)?

☐☐

a. How many of them are younger than 18 years old? ☐☐

b. How many of them are 62 years or older? ☐☐

A15. 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
- ☐ $100,000 or more
- ☐ Don't know
- ☐ Prefer not to answer

A16. Do you currently have health insurance that covers outpatient care and hospital care?

- ☐ Yes
- ☐ No → **Go to Question B1, next page.**
- ☐ Canadian - provincial health insurance → **Go to Question B1, next page.**

A17. What kind of health insurance coverage do you have? (Check all that apply)

- ☐ Individual insurance (through a policy purchased by you/your policy holder)
- ☐ Employer-sponsored insurance (through a policy purchased by your employer or your spouse or significant other's employer)
- ☐ Medicare
- ☐ Medicaid
- ☐ Indian Health Service
- ☐ Military health care (VA or TRICARE)
- ☐ Other state-sponsored health plan
- ☐ Other government program
- ☐ Don't know
- ☐ Other

If Other, please specify:

Please! Do not mark below this line

MEDICAL CARE

B1. During the PAST 2 YEARS, how many times did you see or talk to the following healthcare providers for medical care?

	None	1-2 times	3-4 times	5-10 times	11-20 times	More than 20 times
a. Primary care doctor in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)	☐	☐	☐	☐	☐	☐
b. Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)	☐	☐	☐	☐	☐	☐
c. Other medical specialist (e.g., endocrinologist, cardiologist, surgeon)	☐	☐	☐	☐	☐	☐
d. Psychiatrist	☐	☐	☐	☐	☐	☐
e. Psychologist or counselor	☐	☐	☐	☐	☐	☐
f. Physical or occupational therapist	☐	☐	☐	☐	☐	☐
g. Other specify: _____	☐	☐	☐	☐	☐	☐
h. Other specify: _____	☐	☐	☐	☐	☐	☐

B2. When was the LAST TIME you saw a healthcare provider (e.g., doctor, nurse practitioner, physician's assistant) in each of the following locations where the provider asked you questions or examined you to see whether you had any health problems from your cancer or your cancer treatment?

	Less than 1 year ago	1-2 years ago	More than 2 but less than 5 years ago	5 or more years ago	Never
a. At a cancer survivor clinic	☐	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐	☐

B3. At your LAST check-up at each of the places in the previous question, did your healthcare provider give you advice about what to do to reduce your risks or discuss/order medical screening tests?

	Yes	No	Not sure	Never had a check-up there
a. At a cancer survivor clinic	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐

Please! Do not mark below this line

B4. When do you plan to have your NEXT visit with a doctor or other healthcare provider 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
- ☐ Don't know

B5. Do you currently have a cancer survivorship care plan and/or a summary of treatment for your cancer (records from your cancer doctor that have details about your cancer treatment and medical tests you should have to check for future health problems)?

☐ No ☐ Yes ☐ Not sure

B6. Does your primary care doctor have a copy of your cancer survivorship care plan and/or a summary of your treatment for your cancer?

- ☐ I don't have a primary care doctor
- ☐ I have a primary care doctor but he/she does not have a copy of my cancer survivorship care plan and/or a summary of my treatment for my cancer
- ☐ Yes
- ☐ Not sure

MEDICAL TESTS

C1. The following questions are about medical screening tests you may have received.

When was the last time you had . . .

	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	I had one, but I don't recall when	I don't know if I ever had one
a. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a MUGA scan?	☐	☐	☐	☐	☐	☐	☐
b. An MRI of your heart (you were placed inside of a scanner, like a long tube)?	☐	☐	☐	☐	☐	☐	☐
c. An MRI of the head or brain?	☐	☐	☐	☐	☐	☐	☐
d. A test to measure your bone strength or bone mineral density (such as a DEXA scan)?	☐	☐	☐	☐	☐	☐	☐
e. A home blood stool test to determine whether your stool contains blood?	☐	☐	☐	☐	☐	☐	☐
f. Sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems?	☐	☐	☐	☐	☐	☐	☐
g. An ultrasound of the thyroid gland?	☐	☐	☐	☐	☐	☐	☐
h. An ultrasound of the carotid arteries (blood vessels in the neck)?	☐	☐	☐	☐	☐	☐	☐
i. A skin exam for skin cancer by a healthcare provider?	☐	☐	☐	☐	☐	☐	☐
For females							
j. A mammogram?	☐	☐	☐	☐	☐	☐	☐
k. A breast ultrasound?	☐	☐	☐	☐	☐	☐	☐
l. A breast MRI?	☐	☐	☐	☐	☐	☐	☐
m. A pap smear?	☐	☐	☐	☐	☐	☐	☐
For males							
n. A PSA or blood test to detect prostate cancer?	☐	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

C2. Please indicate all medicines/drugs you took regularly during the PAST 2 YEARS.

- We are only asking about medicines/drugs that 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).

	Please specify the name of each prescription medicine/drug that you have taken in the spaces below, writing the name (generic or specific) of one drug in each box. If you don't know the drug name, please describe what the drug was prescribed for. **Prescription medicine/drug name**	**Age at first use**	**Are you currently taking?**	
			Yes	**No**
1			☐	☐
2			☐	☐
3			☐	☐
4			☐	☐
5			☐	☐
6			☐	☐
7			☐	☐
8			☐	☐
9			☐	☐
10			☐	☐
11			☐	☐
12			☐	☐
13			☐	☐
14			☐	☐
15			☐	☐
16			☐	☐
17			☐	☐
18			☐	☐
19			☐	☐
20			☐	☐

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.

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

If yes, describe the other hearing problem(s). List the age at first occurrence for each problem separately.

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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
D9. Legally blind in both eyes?	☐	☐	☐	☐	

If yes, do you have any sight?
☐ No ☐ Yes

D10. Cataracts?	☐	☐	☐	☐	
D11. Glaucoma (excess pressure in the eyeball)?	☐	☐	☐	☐	
D12. Problems with double vision?	☐	☐	☐	☐	
D13. A detached retina or any other condition of the retina?	☐	☐	☐	☐	

If yes, describe the other condition(s). List the age at first occurrence for each condition separately.

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 the other eye problem(s). List the age at first occurrence for each problem separately.

Please! Do not mark below this line

Please 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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
D19. Stammering or stuttering speech?	☐	☐	☐	☐	☐☐
D20. Any other speech defects?	☐	☐	☐	☐	

If yes, describe the other speech defect(s). List the age at first occurrence for each defect separately.

D21. Abnormal sense of taste?	☐	☐	☐	☐	☐☐
D22. Loss of taste or smell lasting for 3 months or more?	☐	☐	☐	☐	☐☐

URINARY SYSTEM

E1. Kidney stones?	☐	☐	☐	☐	☐☐
E2. REPEATED kidney or bladder infections (more than 3 in any 12 month period)?	☐	☐	☐	☐	☐☐
E3. Dialysis?	☐	☐	☐	☐	☐☐
E4. Blood in your urine?	☐	☐	☐	☐	☐☐
E5. Urinary incontinence?	☐	☐	☐	☐	☐☐
E6. Any other kind of kidney, bladder or urinary tract disorder?	☐	☐	☐	☐	

If yes, describe the other disorder(s). List the age at first occurrence for each disorder separately.

HEART AND CIRCULATORY SYSTEM

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	If yes, age at first occurrence
F1. Congestive heart failure or cardiomyopathy (weak heart muscle)?	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ ☐				
F2. A myocardial infarction (heart attack)?	☐	☐	☐	☐☐
F3. Irregular heartbeat or palpitations (arrhythmia) requiring medication or follow-up by a doctor?	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ ☐				
F4. Coronary heart disease?	☐	☐	☐	

If yes, describe the type of problem(s). List the age at first occurrence for each problem separately.

If yes, do you currently take medication for this? ☐ ☐

					If yes
F5. Hypertension (high blood pressure) requiring medication?	☐	☐	☐	☐	☐☐

If yes, do you currently take hypertension medication? ☐ No ☐ Yes

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
F6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
F7. Pericarditis or fluid around the heart?	☐	☐	☐	☐	☐☐
F8. Pericardial constriction (scarring or tightness of the sac around the heart)?	☐	☐	☐	☐	☐☐
F9. Stiff or leaking heart valves?	☐	☐	☐	☐	☐☐
F10. Blood clot in head, lung, arm, leg, or pelvis?	☐	☐	☐	☐	☐☐
F11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat?	☐	☐	☐	☐	☐☐
F12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
F13. Any other heart or circulatory problems?	☐	☐	☐	☐	☐☐

If yes, describe the other problem(s). List the age at first occurrence for each problem separately.

F14. Has anyone in your immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?

☐ No ☐ Yes ☐ Unsure

HORMONAL SYSTEMS

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
G1. An overactive thyroid gland (hyperthyroid)?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
G2. An underactive thyroid gland (hypothyroid)?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
G3. Thyroid nodules?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
G4. Swollen or enlarged thyroid gland?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
G5. Diabetes that can be controlled with diet?	☐	☐	☐	☐	☐☐
G6. Diabetes controlled with pills or tablets?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					
G7. Diabetes controlled with insulin shots?	☐	☐	☐	☐	☐☐
If yes, do you currently take medication for this? ☐ No ☐ Yes					

Please! Do not mark below this line

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	Not sure	If yes, age at first occurrence
G8. Deficiency of growth hormone?	☐	☐	☐	☐ ☐
G9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?	☐	☐	☐	☐ ☐

If yes, do you currently take injections of growth hormone?
☐ No ☐ Yes

	No	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
G10. Any other hormonal problems?	☐	☐	☐	☐ ☐

If yes, describe the other hormonal problem(s). List the age at first occurrence for each problem separately.

	No	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
G11. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?	☐	☐	☐	☐ ☐
G12. Have you ever broken a bone?	☐	☐	☐	

If yes, describe all occurrences of broken bones. List the age for each individual occurrence.

Males → Go to Question H1.

G13. **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 G15.

G14. **FEMALES** - At what age did you last have a menstrual period naturally, without needing hormones or medication?

☐☐ **years and** ☐☐ **months old**

G15. **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. My menstrual periods are irregular but I am not using birth control pills or female hormones to regulate my periods
- ☐ e. I am currently pregnant
- ☐ f. I am not having menstrual periods naturally but I am taking birth control pills or female hormones
- ☐ g. I am not having menstrual periods naturally and I am not taking birth control pills or female hormones
- ☐ h. Other

If Other, please describe.

If you selected a, b, c, d, or e → Go to Question H1.

If you selected f, g, or h → Go to Question G16.

Please! Do not mark below this line

G16. **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.

RESPIRATORY SYSTEM

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
H1. Asthma?	☐	☐	☐	☐	
H2. Chronic cough or shortness of breath for more than one month?	☐	☐	☐	☐	
H3. A need for extra oxygen?	☐	☐	☐	☐	
H4. Pneumonia, 3 or more times in the past 2 years?	☐	☐	☐	☐	
H5. Emphysema or other chronic obstructive pulmonary disease (COPD)?	☐	☐	☐	☐	
H6. Lung fibrosis or "scarring" of the lung?	☐	☐	☐	☐	
H7. Problems with breathing while at rest that lasted for more than 3 months?	☐	☐	☐	☐	
H8. Any other breathing or lung problems?	☐	☐	☐	☐	

If yes, describe the other problem(s). List the age at first occurrence for each problem separately.

Please mark an answer for each of the following questions, to help ensure the accuracy of our research results.

DIGESTIVE SYSTEM

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
I1. Hepatitis?	☐	☐	☐	☐	
I2. Cirrhosis of the liver?	☐	☐	☐	☐	
I3. Fatty liver?	☐	☐	☐	☐	
I4. Any other liver trouble?	☐	☐	☐	☐	
I5. Intestinal (colon) polyps?	☐	☐	☐	☐	
I6. Esophageal strictures (narrowing of the esophagus)?	☐	☐	☐	☐	
I7. Rectal or anal fistula?	☐	☐	☐	☐	
I8. Rectal or anal stricture (narrowing or scarring)?	☐	☐	☐	☐	
I9. Any other stomach or digestive trouble?	☐	☐	☐	☐	

If yes, what type(s)? (Check all that apply)

- ☐ Hepatitis A
- ☐ Hepatitis B
- ☐ Hepatitis C
- ☐ Don't know
- ☐ Other

If yes, describe the other liver problem(s). List the age at first occurrence for each problem separately.

If yes, describe the other problem(s). List the age at first occurrence for each problem separately.

Please! Do not mark below this line

Please do not leave any answers blank. This will increase the accuracy of our findings.

BRAIN AND NERVOUS SYSTEM

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
J1. Problems with learning or memory?	☐	☐	☐	☐	
J2. Epilepsy, repeated seizures, convulsions, or blackouts?	☐	☐	☐	☐	

If yes, describe the problem(s) and list medications. List the age at first occurrence for each problem separately.

If yes, are you currently taking medication for this?
☐ No ☐ Yes

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
J3. Migraine?	☐	☐	☐	☐	
J4. Other severe headaches?	☐	☐	☐	☐	

If yes, list medications if required to control migraine or other severe headaches.

					If yes
J5. Problems with balance, equilibrium, or ability to reach for or manipulate objects?	☐	☐	☐	☐	

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

☐ Mild; does not affect walking or my daily routine.

☐ Moderate; it is bothersome and affects my walking but I am able to do my daily routine.

☐ Severe; this problem significantly affects my walking and my daily routine.

☐ Disabling; I require a wheelchair or cannot walk because of this problem.

					If yes
J6. Tremors or problems with movements?	☐	☐	☐	☐	
J7. Problems chewing or swallowing solids or liquids?	☐	☐	☐	☐	
J8. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
J9. Prolonged pain in arms, legs or back?	☐	☐	☐	☐	
J10. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
J11. Weakness or inability to move arm(s)?	☐	☐	☐	☐	
J12. Weakness or inability to move leg(s)?	☐	☐	☐	☐	

Please! Do not mark below this line

Please 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, and the condition is still present	Yes, but the condition is no longer present	Not sure
J13. Paralysis of any kind?.	☐	☐	☐	☐

If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes
J14. A stroke?.	☐	☐	☐	☐	

If no, → Go to Question J15.

If yes, as a result of the stroke . . .

a. Did the symptoms last more than 24 hours? ☐ No ☐ Yes					
b. Did it affect:					
Speech.	☐	☐	☐	☐	
Only one side of the body . .	☐	☐	☐	☐	
Both sides of the body	☐	☐	☐	☐	
c. Did you lose consciousness? ☐ No ☐ Yes					
d. Did you have weakness or inability to move arm(s)?. . .	☐	☐	☐	☐	
e. Did you have weakness or inability to move leg(s)?. . . .	☐	☐	☐	☐	
f. Did you have paralysis of any kind?.	☐	☐	☐	☐	

If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure
J15. Any other brain or nervous system problems?	☐	☐	☐	☐

If yes, describe the other problem(s). List the age at first occurrence for each problem separately.

SURGICAL PROCEDURES

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

	No	Yes	Not sure	If yes
K1. Amputation of an arm, leg, hand, foot?.	☐	☐	☐	

If yes, specify (example: left hand, right foot). List the age for each amputation separately.

K2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)?.	☐	☐	☐	
K3. Other surgery of spinal cord or spine?.	☐	☐	☐	

If yes, specify all surgeries of the spinal cord or spine. List the age at which each surgery occurred.

Please! Do not mark below this line

Please mark an answer for each of the following questions, to help ensure the accuracy of our research results.

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

	No	Yes	Not sure	If yes, age at first occurrence
K4. Leg lengthening or shortening procedures?	☐	☐	☐	☐☐
K5. Joint replacement?	☐	☐	☐	

If yes, specify all joint replacements. List the age at which each joint replacement occurred.

				If yes
K6. Other bone surgery?	☐	☐	☐	

If yes, specify all other bone surgeries. List the age at which each bone surgery occurred.

				If yes
K7. Coronary artery bypass surgery?	☐	☐	☐	☐☐
K8. Pericardiectomy (stripping of the sac around the heart)?	☐	☐	☐	☐☐
K9. Heart catheterization ("heart cath")?	☐	☐	☐	☐☐
K10. Angioplasty (enlarging a heart vessel using a balloon) or stent placement to keep vessel open?	☐	☐	☐	☐☐
K11. Surgery for heart valve replacement?	☐	☐	☐	☐☐
K12. Surgery for pacemaker?	☐	☐	☐	☐☐

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

	No	Yes	Not sure
K13. Other heart surgery?	☐	☐	☐

If yes, specify all other heart surgeries. List the age at which each heart surgery occurred.

				If yes
K14. Surgery for intestinal obstruction (blocked intestines)?	☐	☐	☐	☐☐
K15. Colostomy or ileostomy (stool going into a bag)?	☐	☐	☐	☐☐
K16. Removal of part or all of the colon	☐	☐	☐	☐☐
K17. Removal of part or all of the rectum	☐	☐	☐	☐☐
K18. Biopsy or removal of lump in thyroid gland?	☐	☐	☐	☐☐
K19. Removal of part or all of the thyroid gland?	☐	☐	☐	☐☐
K20. Removal of the spleen?	☐	☐	☐	☐☐
K21. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid?	☐	☐	☐	☐☐
K22. Breast biopsy?	☐	☐	☐	☐☐
K23. Breast-conserving or breast-sparing surgery (lumpectomy)?	☐	☐	☐	☐☐

Please! Do not mark below this line

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

	No	Yes	Not sure	If yes, age at first occurrence
K24. Mastectomy or removal of a breast?	☐	☐	☐	☐☐

If yes, was one or both breasts removed?
- ☐ Left only
- ☐ Right only
- ☐ Both

K25. Lung surgery?	☐	☐	☐	

If yes, specify all lung surgeries. List the age at which each lung surgery occurred.

				If yes
K26. Periodontal (gum) surgery?	☐	☐	☐	☐☐
K27. Heart transplant?	☐	☐	☐	☐☐
K28. Lung transplant?	☐	☐	☐	☐☐
K29. Kidney transplant?	☐	☐	☐	☐☐
K30. Liver transplant?	☐	☐	☐	☐☐
K31. Bone marrow transplant?	☐	☐	☐	☐☐
K32. Other organ transplant?	☐	☐	☐	

If yes, specify all other organ transplants. List the age for each individual transplant.

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

	No	Yes	Not sure	If yes, age at first occurrence
K33. Cataract surgery?	☐	☐	☐	☐☐

Males → Go to Question K37.

K34. Removal of one ovary?	☐	☐	☐	☐☐
K35. Removal of both ovaries?	☐	☐	☐	☐☐
K36. Removal of uterus?	☐	☐	☐	☐☐

Females → Go to Question K40.

K37. Removal of one testis?	☐	☐	☐	☐☐
K38. Removal of both testes?	☐	☐	☐	☐☐
K39. Removal of part or all of the prostate gland (prostatectomy)	☐	☐	☐	☐☐
K40. Any other surgery?	☐	☐	☐	

If yes, specify all other surgeries. List the age at which each other surgery occurred.

Please! Do not mark below this line

FEELINGS/EMOTIONS

Questions L1 to L18 relate to the <u>past 7 days</u>.

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 <u>during the past 7 days</u> 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.	☐	☐	☐	☐	☐
L2. Faintness or dizziness.	☐	☐	☐	☐	☐
L3. Pains in heart or chest.	☐	☐	☐	☐	☐
L4. Thoughts of ending your life	☐	☐	☐	☐	☐
L5. Suddenly scared for no reason.	☐	☐	☐	☐	☐
L6. Feeling lonely.	☐	☐	☐	☐	☐
L7. Feeling blue.	☐	☐	☐	☐	☐
L8. Feeling no interest in things	☐	☐	☐	☐	☐
L9. Feeling fearful	☐	☐	☐	☐	☐
L10. Nausea or upset stomach.	☐	☐	☐	☐	☐
L11. Trouble getting your breath.	☐	☐	☐	☐	☐
L12. Numbness or tingling in parts of your body.	☐	☐	☐	☐	☐
L13. Feeling hopeless about the future. . .	☐	☐	☐	☐	☐
L14. Feeling weak in parts of your body . .	☐	☐	☐	☐	☐
L15. Feeling tense or keyed up.	☐	☐	☐	☐	☐
L16. Spells of terror or panic.	☐	☐	☐	☐	☐
L17. Feeling so restless you couldn't sit still.	☐	☐	☐	☐	☐
L18. Feelings of worthlessness.	☐	☐	☐	☐	☐

L19. Please select a response for each item.

In the past 7 days...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. My mind has been as sharp as usual.	☐	☐	☐	☐	☐
b. My memory has been as good as usual.	☐	☐	☐	☐	☐
c. My thinking has been as fast as usual.	☐	☐	☐	☐	☐
d. I have been able to keep track of what I am doing, even if I am interrupted.	☐	☐	☐	☐	☐

L20. Please select a response for each item.

	Never	Rarely	Sometimes	Usually	Always
a. I feel left out.	☐	☐	☐	☐	☐
b. I feel that people barely know me. . .	☐	☐	☐	☐	☐
c. I feel isolated from others.	☐	☐	☐	☐	☐
d. I feel that people are around me but not with me.	☐	☐	☐	☐	☐

L21. 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

L22. Do you currently have pain as a result of your cancer or similar illness, or its treatment?

- ☐ No pain
- ☐ Small amount of pain
- ☐ Medium amount of pain
- ☐ A lot of pain
- ☐ Very bad, excruciating pain

Please! Do not mark below this line

HEALTH HABITS

Alcohol

M1. In your entire life, have you ever had at least 2 drinks of any kind of alcoholic beverage?

☐ No → **Go to Question M7.**

☐ Yes

M2. How old were you when you first started drinking alcohol?

☐☐ years old

M3. 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):
☐☐	☐☐	☐☐
Glasses a day	Cans a day	Drinks a day

M4. During the last 12 months, what is the largest number of drinks you had on any single day?

☐ 24+ drinks

☐ 12-23 drinks

☐ 8-11 drinks

☐ 5-7 drinks

☐ 4 drinks

☐ 3 drinks

☐ 2 drinks

☐ 1 drink

☐ 0 drinks → **Go to Question M7.**

M5. 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

M6. 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

The following questions are referring to cigarettes containing tobacco.

M7. Have you smoked at least 100 cigarettes since you last provided us this information on

☐ No → **Go to Question M13, next page.**

☐ Yes

M8. How old were you when you started smoking?

☐☐

Please! Do not mark below this line

M9. Do you smoke cigarettes now?

☐ No

☐ Yes

M10. On average, how many cigarettes a day do/did you smoke?

☐☐

M11. How many years, in total, have you smoked?

☐☐

M12. 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?

☐☐

M13. In the past year, have you ever used any of these products? (Mark all that apply)

	Never used	No longer use	Occasionally use	Regularly use
Chewing tobacco	☐	☐	☐	☐
Snuff tobacco	☐	☐	☐	☐
Pipes	☐	☐	☐	☐
Cigars	☐	☐	☐	☐
E-cigarettes/Vaping	☐	☐	☐	☐

If you have never used any of these products, → Go to Question M15.

M14. 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	☐	☐	☐	☐	☐
Snuff tobacco	☐	☐	☐	☐	☐
Pipes	☐	☐	☐	☐	☐
Cigars	☐	☐	☐	☐	☐
E-cigarettes/Vaping	☐	☐	☐	☐	☐

Physical Activity

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

M15. During the past month, did you participate in any physical activities or exercises such as running, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No

☐ Yes

We are interested in three types of physical activity: vigorous, moderate, and light.
- **Vigorous activities cause large increases in breathing or heart rate.**
- **Moderate activities cause small increases in breathing or heart rate.**
- **Light activities cause no increase in breathing or heart rate.**

M16. 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 M19.**

☐ Yes

M17. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

☐ Days per week

M18. 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

M19. 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 M22., next page.**

☐ Yes

M20. How many days per week do you do these moderate activities for at least 10 minutes at a time?

☐ Days per week

Please! Do not mark below this line

M21. 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

M22. Now, thinking about the light physical activities you do in a usual week, do you do light activities for at least 10 minutes at a time, such as a slow casual walk, or anything else that does not cause an increase in your breathing or heart rate?

☐ No → **Go to Question M25.**

☐ Yes

M23. How many days per week do you do these light activities for at least 10 minutes at a time?

☐ Days per week

M24. On days when you do light activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

M25. 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

M26. 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

M27. Does any impairment or health problem keep you from holding a job or attending school?

☐ No

☐ Yes

M28. Do you currently have a driver's license?

☐ No

☐ Yes

M29. 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.)	Limited for more than 3 months	Limited for 3 months or less	Not limited at all
a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	☐	☐	☐
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling	☐	☐	☐
c. Walking uphill or climbing a few flights of stairs	☐	☐	☐
d. Bending, lifting, or stooping	☐	☐	☐
e. Walking one block	☐	☐	☐
f. Eating, dressing, bathing, or using the toilet	☐	☐	☐

DAILY ACTIVITIES

Above, we asked you for information on activities in the last two years. This section is about your health and daily activities during the PAST 4 WEEKS. Please try to answer every question as accurately as you can.

N1. In general, would you say your health is:

☐ Excellent

☐ Very good

☐ Good

☐ Fair

☐ Poor

N2. Compared to one year ago, how would you rate your health in general now?

☐ Much better now than one year ago

☐ Somewhat better now than one year ago

☐ About the same as one year ago

☐ Somewhat worse now than one year ago

☐ Much worse now than one year ago

Please! Do not mark below this line

N3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b. Moderate Activities, such as moving a table, bowling, or playing golf	☐	☐	☐
c. Lifting or carrying groceries	☐	☐	☐
d. Climbing several flights of stairs	☐	☐	☐
e. Climbing one flight of stairs	☐	☐	☐
f. Bending, kneeling, or stooping	☐	☐	☐
g. Walking more than a mile	☐	☐	☐
h. Walking several hundred yards	☐	☐	☐
i. Walking one hundred yards	☐	☐	☐
j. Bathing or dressing yourself	☐	☐	☐

N4. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	☐	☐	☐	☐	☐
b. Accomplished less than you would like	☐	☐	☐	☐	☐
c. Were limited in the kind of work or other activities	☐	☐	☐	☐	☐
d. Had difficulty performing the work or other activities (for example, it took extra effort)	☐	☐	☐	☐	☐

N5. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	☐	☐	☐	☐	☐
b. Accomplished less than you would like	☐	☐	☐	☐	☐
c. Did work or activities less carefully than usual	☐	☐	☐	☐	☐

N6. During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

☐ Not at all ☐ Quite a bit

☐ Slightly ☐ Extremely

☐ Moderately

N7. How much bodily pain have you had during the PAST 4 WEEKS?

☐ None ☐ Moderate

☐ Very mild ☐ Severe

☐ Mild ☐ Very severe

N8. 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

Please! Do not mark below this line

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HEALTH AND WELL-BEING

O1. These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please mark the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS. . .

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	☐	☐	☐	☐	☐
b. Have you been very nervous?	☐	☐	☐	☐	☐
c. Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐
d. Have you felt calm and peaceful?.	☐	☐	☐	☐	☐
e. Did you have a lot of energy?	☐	☐	☐	☐	☐
f. Have you felt downhearted and depressed?	☐	☐	☐	☐	☐
g. Did you feel worn out?	☐	☐	☐	☐	☐
h. Have you been happy?	☐	☐	☐	☐	☐
i. Did you feel tired?	☐	☐	☐	☐	☐

O2. During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

☐ All of the time ☐ A little of the time

☐ Most of the time ☐ None of the time

☐ Some of the time

O3. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
b. I am as healthy as anybody I know	☐	☐	☐	☐	☐
c. I expect my health to get worse	☐	☐	☐	☐	☐
d. My health is excellent	☐	☐	☐	☐	☐

PROBLEM SOLVING

P. Below is a list of statements that describe problems people can have. We would like to know if you have had any of these problems over the PAST 6 MONTHS. Please complete all items. Please think about yourself as you read these statements and mark one response on each line.

	Never a problem	Sometimes a problem	Often a problem
1. I get upset easily	☐	☐	☐
2. It takes me longer to complete my work	☐	☐	☐
3. I am disorganized	☐	☐	☐
4. I forget instructions easily	☐	☐	☐
5. I have problems completing my work	☐	☐	☐
6. I have difficulty recalling things I had previously learned (e.g., names, places, events, activities)	☐	☐	☐
7. I get frustrated easily	☐	☐	☐
8. My mood changes frequently.	☐	☐	☐
9. I have trouble finding things in my bedroom, closet or desk	☐	☐	☐
10. I forget what I am doing in the middle of things	☐	☐	☐
11. I have problems getting started on my own	☐	☐	☐
12. I am easily overwhelmed	☐	☐	☐
13. I have trouble doing more than one thing at a time	☐	☐	☐
14. My desk/workspace is a mess	☐	☐	☐
15. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.)	☐	☐	☐
16. I have trouble prioritizing my activities.	☐	☐	☐
17. I read slowly	☐	☐	☐
18. I am slower than others when completing my work	☐	☐	☐
19. I have trouble solving math problems in my head	☐	☐	☐
20. I don't work well under pressure.	☐	☐	☐
21. I have trouble staying on the same topic when talking	☐	☐	☐
22. I have a messy closet	☐	☐	☐
23. People say I am easily distracted	☐	☐	☐
24. I have angry outbursts	☐	☐	☐
25. I have a short attention span	☐	☐	☐
26. I overreact emotionally	☐	☐	☐
27. I have trouble organizing work	☐	☐	☐
28. I overreact to small problems	☐	☐	☐
29. I have problems organizing activities.	☐	☐	☐
30. I have emotional outbursts for little reason	☐	☐	☐
31. I leave the bathroom a mess	☐	☐	☐
32. I react more emotionally to situations than my friends	☐	☐	☐
33. I leave my room or home a mess	☐	☐	☐

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMOR

R1. Have you been diagnosed with another cancer, leukemia, tumor, skin cancer, or a recurrence (relapse) since you last provided us information in %LastMo%, %LastYr%?

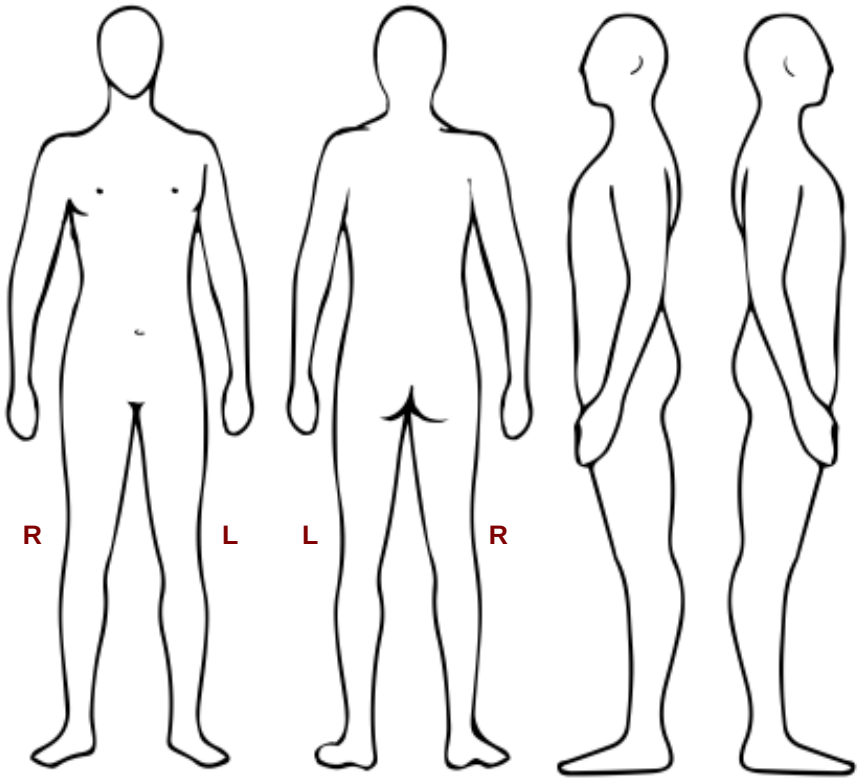
☐ No → **Go to Question S1, page 25.**

☐ Yes

R2. What was the name of this disease?

R3. Where was it located? (Example: right upper arm, left ear)

If the condition in item R2 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.



front view back view left side view right side view

R4. Where was this diagnosed?

Doctor's name
Hospital or clinic
Address
City, State, Zip code

R5. 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 this space to provide any additional details on tumor location.

Please! Do not mark below this line

R6. Have you had more than one additional cancer, leukemia, tumor, or skin cancer since %LastMo%, %LastYr%?

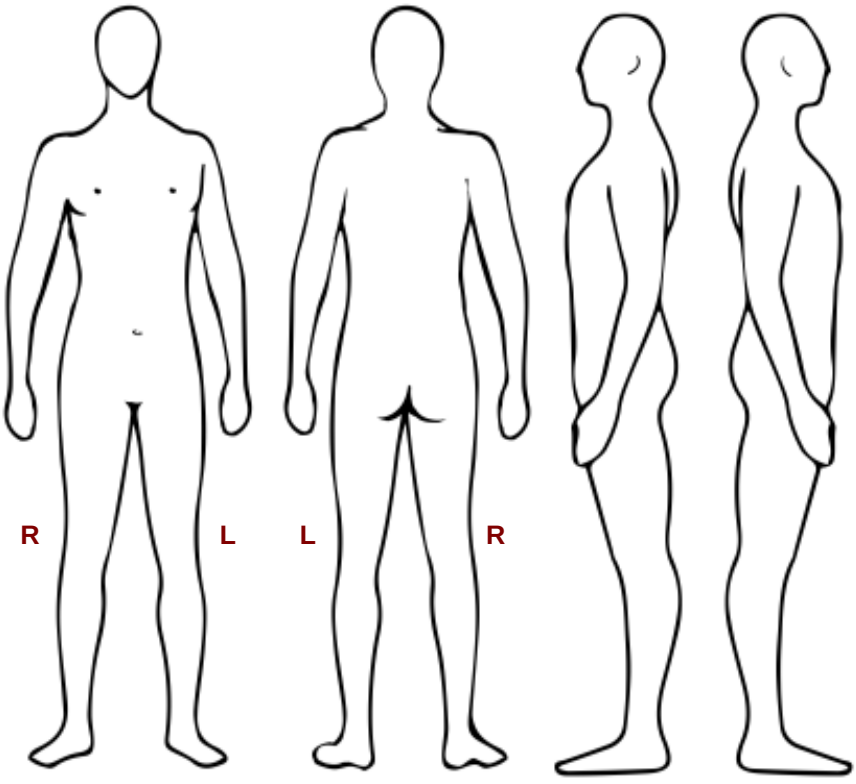
☐ No → **Go to Question S1, next page.**

☐ Yes

R7. What was the name of this disease?

R8. Where was it located? (Example: right upper arm, left ear)

If the condition in item R7 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.



front view back view left side view right side view

R9. Where was this diagnosed?

Doctor's name
Hospital or clinic
Address
City, State, Zip code

R10. 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

Please use this space to provide any additional details on tumor location.

Please! Do not mark below this line

TREATMENT FOR NEW OR RECURRENT TUMOR OR CANCER

We are interested in whether you have had any recent 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.

S1. Have you received any radiation treatment since {LASTDATE}?

- ☐ No → **Go to Question S2.**
- ☐ Yes
- ☐ Not sure

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

Date of Treatment

Month (mm) Year (yyyy)

b. Please indicate the reason for radiation.

c. Where did you receive the radiation treatment?

Hospital or clinic
Address
City, State, Zip code
Doctor's name

S2. Have you received any chemotherapy treatment since {LASTDATE}?

- ☐ No → **Go to Question T1, next page.**
- ☐ Yes
- ☐ Not sure

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

Date of Treatment

Month (mm) Year (yyyy)

b. Please indicate the reason for chemotherapy.

c. Where did you receive the chemotherapy treatment?

Hospital or clinic
Address
City, State, Zip code
Doctor's name

Please! Do not mark below this line

EMERGENCY ROOM (ER) VISITS

We are interested in any emergency room (ER) visits that you may have had in the last 12 months.

T1. Have you been to the ER in the last 12 months?

☐ No → **Go to Section U, next page.**

☐ Yes

T2. How many times have you been to the ER in the last 12 months? ☐☐

T3. What was the main reason for the first ER visit?

a. If there were other reasons please list them here.

b. Date of first ER visit:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. Did this ER visit result in being admitted to the hospital?

☐ No

☐ Yes

If you have been to the ER more than once in the last 12 months. . .

T4. What was the main reason for the second ER visit?

a. If there were other reasons please list them here.

b. Date of second ER visit:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. Did this ER visit result in being admitted to the hospital?

☐ No

☐ Yes

Please use a separate sheet of paper for additional ER visits

HOSPITALIZATIONS

We are interested in any admissions to the hospital for illness, surgical, or diagnostic procedures, including psychiatric/mental health hospitalization or short stays of 24 hours or less that you may have had in the last 12 months. DO NOT INCLUDE PREGNANCY RELATED ADMISSIONS or EMERGENCY ROOM VISITS.

U1. Have you been admitted to a hospital in the last 12 months?

☐ No → **Go to Section V, next page.**

☐ Yes

U2. How many times have you been admitted to a hospital in the last 12 months? ☐☐

U3. What was the main reason for the first hospitalization?

a. If there were other reasons please list them here.

b. Date of first hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. How long did you stay in the hospital?

☐☐ Days

If you were admitted to the hospital more than once in the last 12 months. . .

U4. What was the main reason for the second hospitalization?

a. If there were other reasons please list them here.

b. Date of second hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. How long did you stay in the hospital?

☐☐ Days

Please use a separate sheet of paper for additional hospitalizations

PREGNANCY AND OFFSPRING

Female

V1. Have you had any new pregnancies since you last provided us with this information on {LASTDATE}?

☐ No → **Go to page 29.**

☐ Yes

V2. Are you currently pregnant?

☐ No

☐ Yes

Continue to Question V5 below.

Male

V3. Has a woman been pregnant by you since you last provided us with this information on {LASTDATE}?

☐ No → **Go to page 29.**

☐ Yes

V4. Is she currently pregnant?

☐ No

☐ Yes

Continue to Question V5 below.

V5. Since {LASTDATE}, 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	Currently pregnant	Your age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
Pregnancy 1.	☐	☐	☐	☐	☐			
Pregnancy 2.	☐	☐	☐	☐	☐			
Pregnancy 3.	☐	☐	☐	☐	☐			
Pregnancy 4.	☐	☐	☐	☐	☐			
Pregnancy 5.	☐	☐	☐	☐	☐			
Pregnancy 6.	☐	☐	☐	☐	☐			
Pregnancy 7.	☐	☐	☐	☐	☐			
Pregnancy 8.	☐	☐	☐	☐	☐			

Please attach a separate sheet of paper, if more than 8 pregnancies

Please! Do not mark below this line

GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions that you have. Indicate "Yes" only if a physician has told you that you were born with, or have the condition.

Because we need definite responses, and questions left blank are difficult to interpret, it is very important that you mark an answer for each of the following questions, even if you have never had that condition. If you have never heard of these conditions, it is unlikely that you have had them.

W1a. Have you ever been told by a doctor that you have. . .

	No	Yes	Not sure
a. Ataxia telangiectasia	☐	☐	☐
b. Beckwith-Wiedemann syndrome	☐	☐	☐
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2)	☐	☐	☐
d. Bloom's syndrome	☐	☐	☐
e. Down syndrome	☐	☐	☐
f. Klinefelter's syndrome	☐	☐	☐
g. Fanconi's anemia	☐	☐	☐
h. Multiple exostoses	☐	☐	☐
i. Familial adenomatous polyposis (FAP or Gardner syndrome)	☐	☐	☐
j. Neurofibromatosis (Type 1)	☐	☐	☐
k. Nevoid basal cell carcinoma syndrome	☐	☐	☐
l. Turner's syndrome	☐	☐	☐
m. Von Hippel-Lindau syndrome	☐	☐	☐
n. Wiskott-Aldrich syndrome	☐	☐	☐
o. Xeroderma pigmentosum	☐	☐	☐
p. Any other genetic disorder	☐	☐	☐

If yes, describe this disorder.

W1b. Has anyone in your immediate family (blood relatives only) ever had any of the conditions in Question W1a? (Mark all that apply)

What conditions?

- ☐ Mother →
- ☐ Father →
- ☐ Full brother →
- ☐ Full sister →
- ☐ Son →
- ☐ Daughter →

W2. Has anyone in your immediate family (blood relatives only) ever had cancer? (Mark all that apply)

What types?

- ☐ Mother →
- ☐ Father →
- ☐ Full brother →
- ☐ Full sister →
- ☐ Son →
- ☐ Daughter →

Please! Do not mark below this line

1. Do you use a cell phone?

☐ Yes ☐ No → **Skip Question 2. Continue below to verify or update your contact information.**

1a. Would you be willing to send/receive study-related texts?

☐ Yes ☐ No ☐ My phone is not text capable

Your phone number: ( ) -

2. Do you use a "smartphone" that can access the internet or download "apps" (e.g. iPhone, Android, Blackberry, Windows)?

☐ Yes ☐ No

2a. What type of smartphone do you use?

☐ iPhone ☐ Android (e.g., Samsung, Google Pixel, OnePlus, Motorola, Nokia, LG)

☐ Not sure ☐ Other specify: _____

We want to make sure we can stay in touch with you. Please verify or update your contact information.

We have your current address as:

☐ Correct

☐ Not correct (please update below)

☐ Moving. Anticipated move date:
(provide new address below if known)

m m / d d / y y y y

Address:		
City:	State:	Zip code:

How long have you lived at your current address? _____

Please let us know if these phone numbers are still current. Please also provide us with any updated phone numbers below.

Phone number	Current	Not current
	☐	☐
	☐	☐
	☐	☐

Updated phone numbers:

Home phone:	Other phone number:
Cell phone:	

Please let us know if these email addresses are still current. Please also provide us with any updated email addresses below.

Email address	Current	Not current
	☐	☐
	☐	☐
	☐	☐

Updated email addresses:

Email address 1:
Email address 2:

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.

Name:		
Address:	Relationship to	
City:	State:	Zip code:
Cell phone:	Home phone:	Work phone:

Please! Do not mark below this line

HIPAA Authorization Form

If you sign this form, you are giving St. Jude Children's Research Hospital permission to use or disclose (give out) medical information. It will allow St. Jude to get copies of certain parts of your (your child's) medical record that we may need to review, such as treatment history for your (your child's) childhood illness or records for later illnesses.

LONG-TERM FOLLOW-UP STUDY
HIPAA[1] AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION FOR RESEARCH

1. Purpose. As a research participant and at my request, I give Greg Armstrong, M.D., M.S.C.E., and the researcher's staff permission to use and disclose my (my child's) health information for a research project called Long-Term Follow-Up (LTFU) Study.

2. Individual Health Information to be Used or Disclosed. My (My child's) health information that may be used or disclosed for this research may include my (my child's) medical records.

3. Who May Disclose My (My Child's) Health Information? During this study, the researcher and the researcher's staff may get my (my child's) health information from hospitals, clinics, and health care providers who have treated me.

4. Who May Receive My (My Child's) Health Information? The health information disclosed by researchers and information given by me during the research study may be received and used by Greg Armstrong, M.D., M.S.C.E., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Biorepository (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 form. If I decide not to sign the form, I may not be allowed to take part in this study. However, my decision not to sign this form 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 revoke (take back) this authorization (permission) at any time by sending a written notice of my decision to Dr. Greg Armstrong, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105. If I take back my permission, the researcher may use and disclose only the protected health information already collected for the research study. No further health information about me will be collected by the researcher or disclosed to the researcher for this study.

7. Possible Re-disclosure. After my (my child's) health information is given out under this authorization form, there is a chance that it might be re-disclosed outside this study and no longer covered by this form. However, I understand that the research team and the St. Jude Institutional Review Board (IRB) are very careful to protect my (my child's) privacy and limit the use of information that can identify me (my child). (The IRB is the committee that reviews studies to be sure that the rights and safety of those taking part in the study are protected). In addition, the LTFU study maintains a Certificate of Confidentiality from the National Institute of Health to protect the identity of research subjects.

For those taking part in the research study who are not legal adults, this authorization form will expire when they become legal adults (unless the person taking part in the study has appointed a legal guardian to provide authorization). A new form will be required when the child becomes a legal adult. For a legal adult taking part in this study, this authorization (permission) expires at the end of the study.

I am the research participant, or I am legally authorized to act on behalf of the person taking part in the study.

I have read this information and have received a copy of the form.

! Sign Here

_____
Printed name of research participant

_____
Signature of research participant or legal guardian

_____
Date

Fill in Date

_____
Printed name of legal guardian

_____
Describe how the person signing has authority to act on behalf of the research participant

[1] 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

Thank you for completing your survey!

Please use the postage-paid envelope to mail your survey back to the Long-Term Follow-Up Study. Can't find your envelope? Let us know, we'll gladly send another! See below for our contact information.

You are a valued partner.

Thank you for your dedication and important contributions. As an LTFU participant, you are a partner in historic research. The LTFU Study is the largest study of its kind, and one of the longest-running. The National Cancer Institute describes the LTFU Study as "one of the most powerful NCI-supported research efforts for tracking the needs and health of survivors."

You and the study's more than 24,000 participants are helping to make a difference in the lives of people around the world. Today's survivors and future generations will benefit from the information you provide, and what the study continues to learn.

More information about what we're achieving

On the LTFU Study website **(ltfu.stjude.org)** you will find:

- Research results
- Complete list of more than 300 publications
- Newsletters (downloadable)
- Links to online resources about survivorship, selected by the study team

Questions or comments?

We want to know what you think! You can use the space below to write to us, or contact us by:

- Phone **1-800-775-2167**
- Email **LTFU@stjude.org**
- Online **ltfu.stjude.org**

Another way to share your feedback and suggestions is to become part of the LTFU Study Participant Advisory Council (PAC). Learn more at: **ltfu.stjude.org**.

The LTFU Study Team carefully reads all of the comments that participants provide on their surveys, although we are not able to respond to all of them.

LTFU
Long-Term Follow-Up Study

St. Jude Children's Research Hospital

Please! Do not mark below this line

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