LTFU
Long-Term Follow-Up Study

St. Jude Children's Research Hospital

Thank you for participating in the LTFU Study.

We value your time and commitment.

Your new follow-up survey may take about 20-30 minutes to complete.

The information you provide is important to the study's findings. We want to make it as easy as possible for you to complete your survey. Please choose the option that is easiest for you.

Print

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

Desktop or laptop computer

Your answers will be saved if you get interrupted, so you can return to where you left off.

Go to **www.stjude.org/LTFUsurvey**

Your **password** is:
Your **personalized login ID** is your **date of birth**.

Smartphone or tablet

Questions are formatted for mobile devices, so you can complete it almost anywhere. Use the **link and login** information provided above.

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

FU6L Edit Survey #265 Code **0377138481**

09/30/2019 08:11:44 AM

Your survey is important.

We need your response to ensure the accuracy of our results. The information you provide will:

- **Help survivors live healthier lives**
- **Improve care for children** who are ill, now and for generations to come

We take your privacy seriously.

Be assured that we respect and protect your privacy at all times. Your name or other identifiers will not be used in any report of research results, or released to any person or agency, except the study's investigators.

We'd like to hear from you.

Your questions or feedback about this survey or the study are always welcome. You can use the space provided on the back cover to write to us, or contact us by:

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

Today's date:

☐☐ / ☐☐ / ☐☐☐☐

m m **d d** **y y y y**

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

Please! Do not mark below this line

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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

Medical Care

B1. During the 2 year period between **September 2017 and September 2019,** which of the following healthcare 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 B4.**
☐ Primary care clinician in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)
☐ Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)
☐ Other Medical specialist (e.g., endocrinologist, cardiologist, surgeon)
☐ Psychiatrist
☐ Psychologist or counselor
☐ Physical or occupational therapist
☐ Other

If Other, please specify.

B2. During this 2 year period, how many times did you see a doctor?

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

B3. 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 doctor indicated in question **B2** (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

B4. 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 B5, next page.**

B4a. Where was this check-up? (Mark only one)

☐ At a cancer survivor clinic
☐ At a cancer center, but not in a cancer survivor clinic
☐ At my primary care doctor's office
☐ Other

If Other, please specify.

Please! Do not mark below this line

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B4b. At this check-up, did your doctor give you advice about what to do to reduce risks or discuss/order medical screening tests?

- ☐ No
- ☐ Yes
- ☐ Not sure

B4c. When was the last time that you had a medical visit with a cancer specialist (oncologist)?

- ☐ 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

B4d. When was the last time you had a visit to a special clinic for cancer survivors?

- ☐ 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
- ☐ Don't know

B5. 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
- ☐ Don't know

B6. During the PAST 12 MONTHS, how many times have you gone to a HOSPITAL EMERGENCY ROOM about your own health (This includes emergency room visits that resulted in a hospital admission)?

☐☐ times

B7. 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

B8. Does your local or 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

B9. How often do you carefully check your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?

- ☐ Once a month
- ☐ Every few months
- ☐ Every 6 months
- ☐ Every year
- ☐ Never

B10. In the PAST 12 MONTHS, has your regular healthcare provider carefully examined your whole body for any sign of skin cancer?

- ☐ No
- ☐ Yes
- ☐ Not sure

Please! Do not mark below this line

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?	☐	☐	☐	☐	☐	☐	☐

Continue on next page.

Health Habits

Physical Activity

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

D1. 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.

D2. 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 D5.**

☐ Yes

D3. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

☐☐ Days per week

D4. 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

D5. 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 D8.**

☐ Yes

D6. How many days per week do you do these moderate activities for at least 10 minutes at a time?

☐☐ Days per week

D7. 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

D8. 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 E1, next page.**

☐ Yes

D9. How many days per week do you do these light activities for at least 10 minutes at a time?

☐☐ Days per week

D10. 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

Please! Do not mark below this line

Daily Activities

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.

E1. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

E2. 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

E3. 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	☐	☐	☐

E4. 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)	☐	☐	☐	☐	☐

E5. 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	☐	☐	☐	☐	☐

Please! Do not mark below this line

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Health and Well-Being

E6. 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
- ☐ Slightly
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

E7. How much bodily pain have you had during the PAST 4 WEEKS?

- ☐ None
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

E8. 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
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

F1. 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?	☐	☐	☐	☐	☐

F2. 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

F3. 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	☐	☐	☐	☐	☐

Please! Do not mark below this line

Problem Solving

G. 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	☐	☐	☐

If you answered "Sometimes" or "Often" to any of the questions in **Section G**, to what extent do the problems you may have checked interfere with your ability to function?

	Never	Sometimes	Often	Not applicable
1. In your home	☐	☐	☐	☐
2. At your job	☐	☐	☐	☐
3. In social situations	☐	☐	☐	☐
4. In educational activities	☐	☐	☐	☐

Please! Do not mark below this line

Cancer, Leukemia, or Tumor

H1.

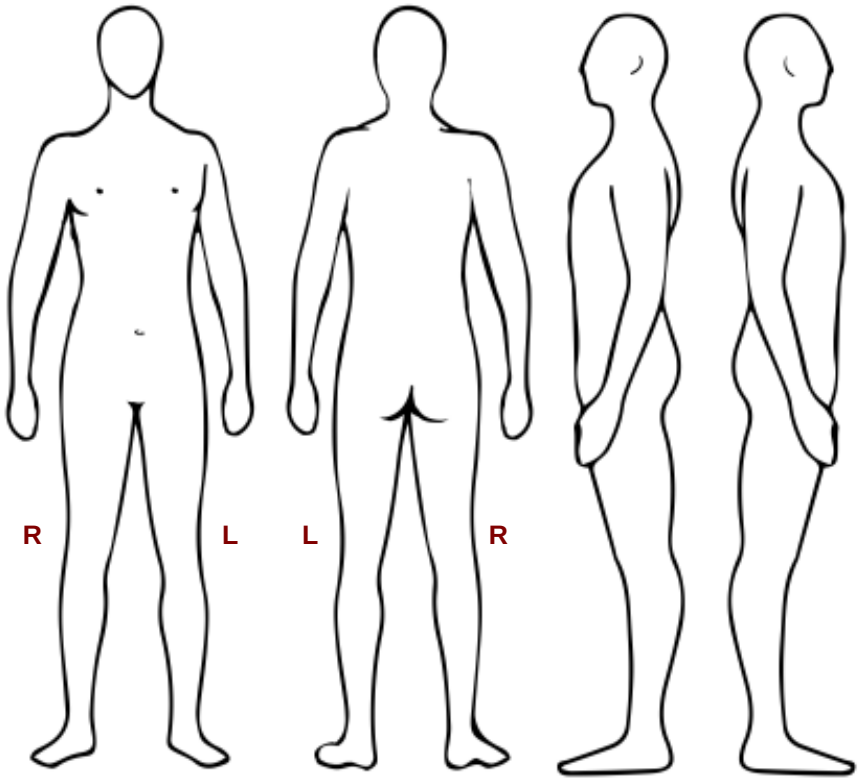
☐ No → **Go to Question I1, page 12.**

☐ Yes

H2. What was the name of this disease?

H3. Where was it located? (Example: right upper arm)

If the condition in item **H2** 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

H4. Where was this diagnosed?

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

H5. 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

H6.

☐ No → **Go to Question I1, next page.**

☐ Yes

H7. What was the name of this disease?

H8. Where was it located? (Example: right upper arm)

H9. Where was this diagnosed?

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

H10. Was this a:

☐ Recurrence of original diagnosis

☐ New cancer, leukemia, tumor, or similar illness

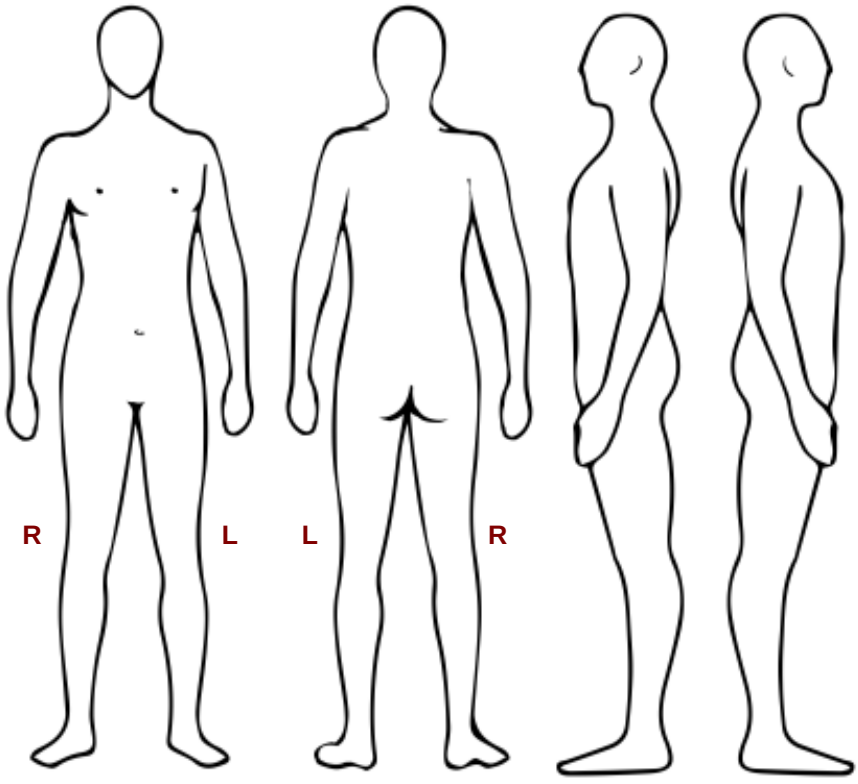
☐ Don't know

Date of Recurrence or New Diagnosis:

Month (mm) Year (yyyy)

If the condition in item **H7** 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.

Please use a separate sheet of paper for additional cancers



front view back view left side view right side view

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

Please! Do not mark below this line

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.

I1. Have you been admitted to a hospital in the last 12 months?

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

☐ Yes

I2. How many times have you been admitted to a hospital in the last 12 months? ☐☐

I3. What was the reason for the first hospitalization?

I3a. What procedures/surgeries were performed?

I3b. Where were you hospitalized?

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

I3c. Date of first hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

I4. What was the reason for the second hospitalization?

I4a. What procedures/surgeries were performed?

I4b. Where were you hospitalized?

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

I4c. Date of second hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

Please use a separate sheet of paper for additional hospitalizations

Please! Do not mark below this line

Sleep Quality

The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month.

J1. During the past month, when have you usually gone to bed at night?

USUAL BED TIME ☐☐ : ☐☐

check one: ☐ **AM** ☐ **PM**

J2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?

NUMBER OF MINUTES ☐☐☐

J3. During the past month, when have you usually gotten up in the morning?

USUAL GETTING UP TIME ☐☐ : ☐☐

check one: ☐ **AM** ☐ **PM**

J4. During the past month, how many hours of actual sleep did you get at night?

HOURS OF SLEEP PER NIGHT ☐☐

J5. During the past month, how often have you had trouble sleeping because you . . .

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
a. Cannot get to sleep within 30 minutes. . .	☐	☐	☐	☐
b. Wake up in the middle of the night or early morning.	☐	☐	☐	☐
c. Have to get up to use the bathroom. . . .	☐	☐	☐	☐
d. Cannot breathe comfortably.	☐	☐	☐	☐
e. Cough or snore loudly.	☐	☐	☐	☐
f. Feel too cold.	☐	☐	☐	☐
g. Feel too hot.	☐	☐	☐	☐
h. Had bad dreams.	☐	☐	☐	☐
i. Have pain.	☐	☐	☐	☐
j. Other reasons.	☐	☐	☐	☐

If Other, please describe:

J6. During the past month, how would you rate your sleep quality overall?

☐ Very good ☐ Fairly bad

☐ Fairly good ☐ Very bad

J7. During the past month . . .

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
a. How often have you taken medicine (prescribed or "over the counter") to help you sleep?.	☐	☐	☐	☐
b. How often have you had trouble staying awake while driving, eating meals, or engaging in social activity?.	☐	☐	☐	☐

J8. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

☐ No problem at all

☐ Only a very slight problem

☐ Somewhat of a problem

☐ A very big problem

J9. Do you have a bed partner or roommate?

☐ No bed partner or roommate → **Go to next page.**

☐ Partner/roommate in other room

☐ Partner in same room, but not same bed

☐ Partner in same bed

J10. If you have a roommate or bed partner, ask him or her how often in the past month you have had . . .

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
a. Loud snoring.	☐	☐	☐	☐
b. Long pauses between breaths while asleep.	☐	☐	☐	☐
c. Legs twitching or jerking while you sleep.	☐	☐	☐	☐
d. Episodes of disorientation or confusion during sleep.	☐	☐	☐	☐
e. Other restlessness while you sleep. . . .	☐	☐	☐	☐

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

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:

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

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Thank you for completing your survey!

We are grateful for your participation and commitment.

Please use the postage-paid envelope to mail your survey back to the Long-Term Follow-Up Study.

Questions or comments?

We welcome your feedback or questions on any aspect of the new survey or the study. Use this space for any additional comments you might have.

You can also contact us anytime:

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

LTFU
Long-Term Follow-Up Study

St. Jude Children's Research Hospital

Please! Do not mark below this line

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