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 child's new follow-up survey may take about 10-15 minutes to complete.

We want to make it as easy as possible for you to complete your child's 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/LTFUsurveyMinor**

Your **password** is:
Your **personalized login ID** is your child's **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

FU6SibMnr Edit Survey #277 Code **9109211171**

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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 child's 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 LTFU 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:

☐ Parent ☐ Other: _____

Please! Do not mark below this line

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Cancer, Leukemia, or Tumor

A1.

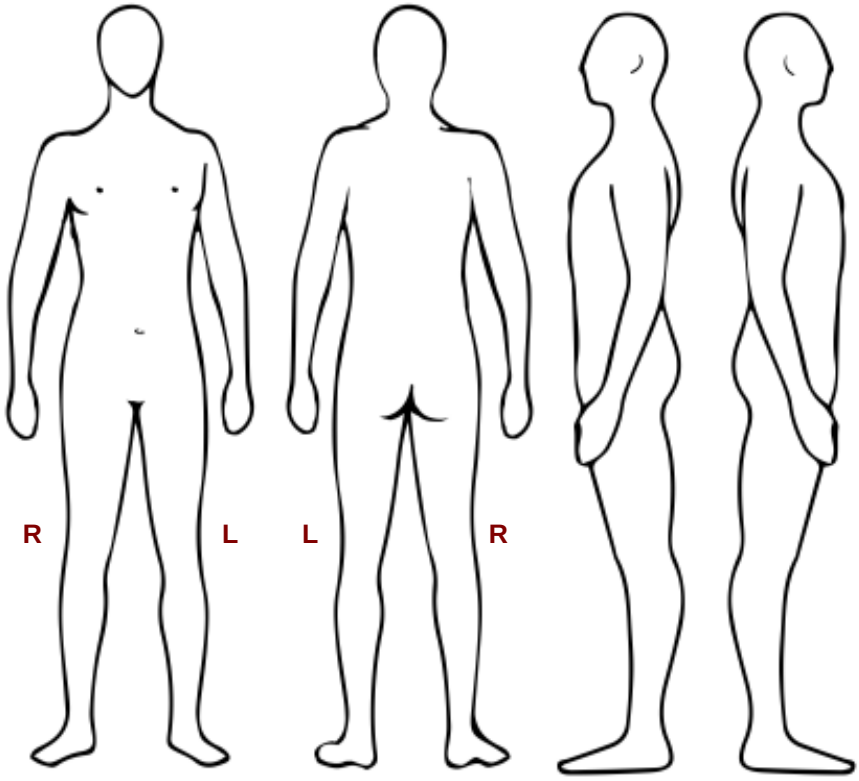
☐ No → **Go to Question B1, page 5.**

☐ Yes

A2. What was the name of this disease?

A3. Where was it located? (Example: right upper arm)

If the condition in item **A2** above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your child's 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

A4. Where was this diagnosed?

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

A5. Was this a:

☐ New cancer, leukemia, tumor, or similar illness

☐ Recurrence of a previous diagnosis

☐ Don't know

Date of 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

A6.

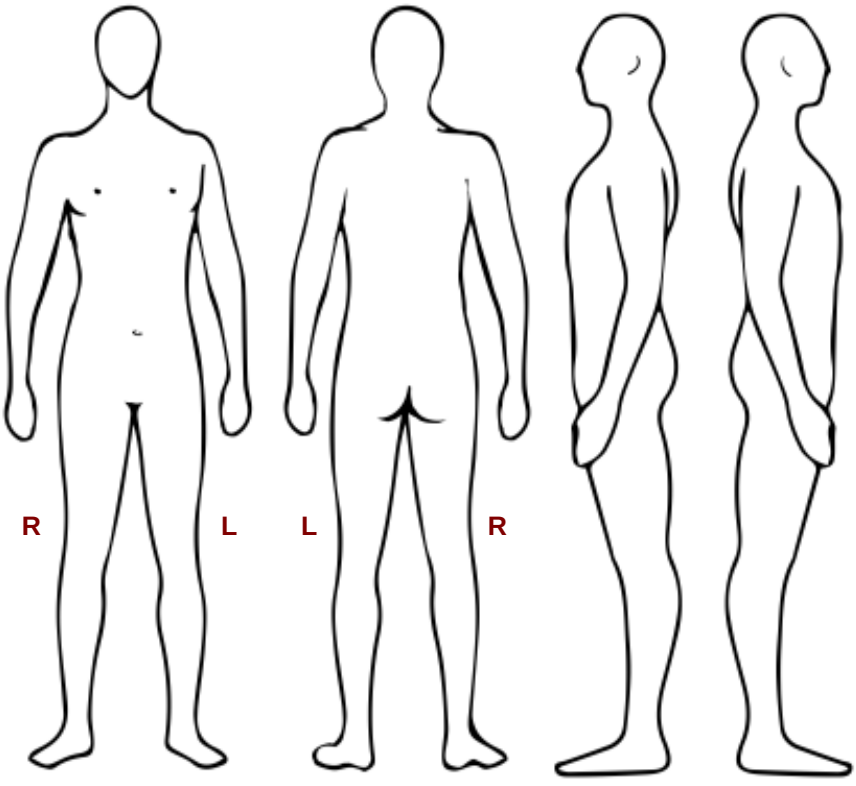
☐ No → **Go to Question B1, next page.**

☐ Yes

A7. What was the name of this disease?

A8. Where was it located? (Example: right upper arm)

If the condition in item **A7** above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your child's cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.



A9. Where was this diagnosed?

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

A10. Was this a:

☐ New cancer, leukemia, tumor, or similar illness

☐ Recurrence of a previous diagnosis

☐ 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

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Sleep Quality

The following questions relate to your child's 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.

B1. During the past month, when has your child usually gone to bed at night?

USUAL BED TIME ☐☐ : ☐☐

check one: ☐ **AM** ☐ **PM**

B2. During the past month, how long (in minutes) has it usually taken your child to fall asleep each night?

NUMBER OF MINUTES ☐☐☐

B3. During the past month, when has your child usually gotten up in the morning?

USUAL GETTING UP TIME ☐☐ : ☐☐

check one: ☐ **AM** ☐ **PM**

B4. During the past month, how many hours of actual sleep did your child get at night?

HOURS OF SLEEP PER NIGHT ☐☐

B5. During the past month, how often has your child had trouble sleeping because he/she . . .

	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. Wakes up in the middle of the night or early morning	☐	☐	☐	☐
c. Has to get up to use the bathroom	☐	☐	☐	☐
d. Cannot breathe comfortably	☐	☐	☐	☐
e. Coughs or snores loudly	☐	☐	☐	☐
f. Feels too cold	☐	☐	☐	☐
g. Feels too hot	☐	☐	☐	☐
h. Had bad dreams	☐	☐	☐	☐
i. Has pain	☐	☐	☐	☐
j. Other reasons	☐	☐	☐	☐

If Other, please describe:

B6. During the past month, how would you rate your child's sleep quality overall?

☐ Very good

☐ Fairly good

☐ Fairly bad

☐ Very bad

B7. 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 has your child taken medicine (prescribed or "over the counter") to help him/her sleep?	☐	☐	☐	☐
b. How often has your child had trouble staying awake while driving, eating meals, or engaging in social activity?	☐	☐	☐	☐

B8. During the past month, how much of a problem has it been for your child 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

Please! Do not mark below this line

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:

THE PARENTS OF

☐ 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**

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