# 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 minutes to complete.

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**

## 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.

**New questions** in this survey will help us learn more about your sleep habits, your current healthcare coverage, and important financial issues that participants and their families may face. 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 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**

**Start here!**

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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# Cancer, Leukemia, or Tumor

**A1.**

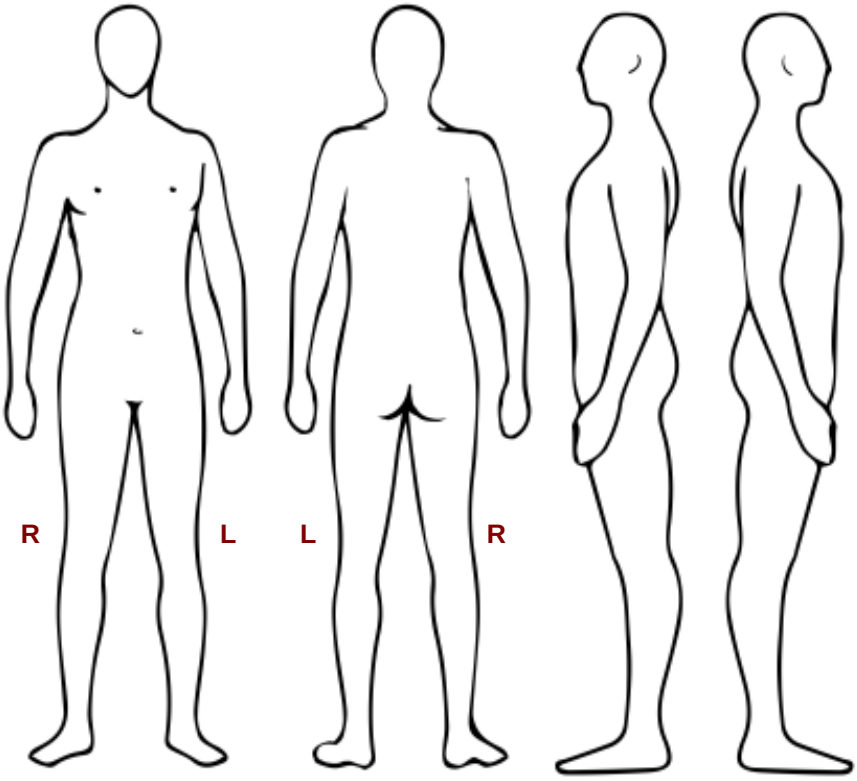
☐ No → **Go to Question B1, page 5.**

☐ 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 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.**

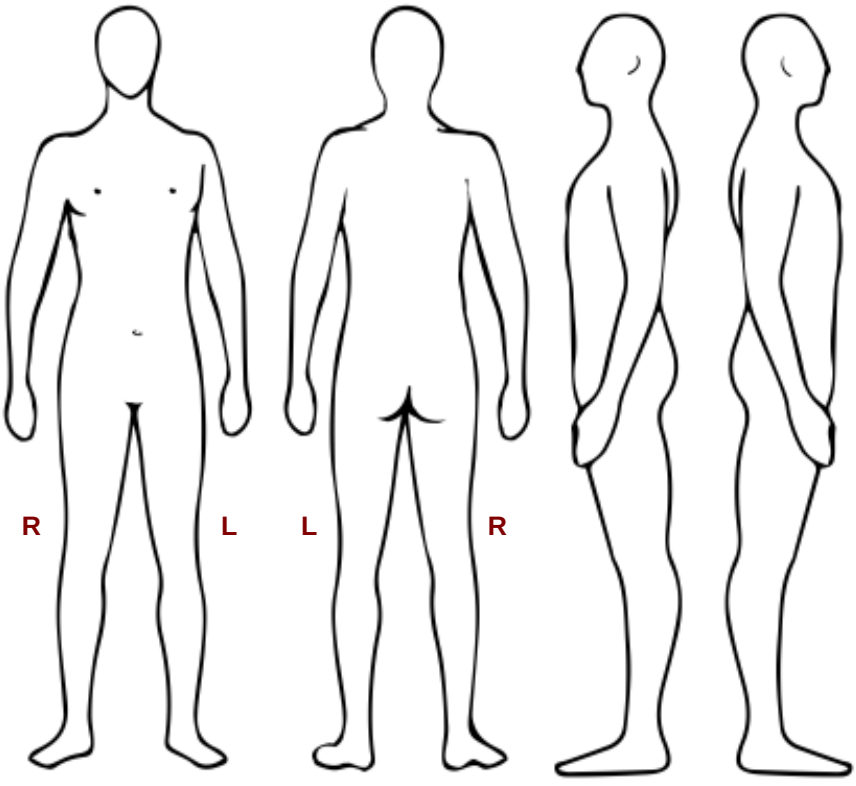
☐ No → **Go to Question B1, next page.**

☐ 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 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 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 have you 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 you to fall asleep each night?

NUMBER OF MINUTES ☐☐☐

**B3.** During the past month, when have you 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 you get at night?

HOURS OF SLEEP PER NIGHT ☐☐

**B5.** 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:**

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

☐ Very good

☐ Fairly good

☐ Fairly bad

☐ Very bad

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

**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 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? | ☐ | ☐ | ☐ | ☐ |

**B8.** 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

**B9.** Do you have a bed partner or roommate?

- ☐ No bed partner or roommate → **Go to Question C1.**
- ☐ Partner/roommate in other room
- ☐ Partner in same room, but not same bed
- ☐ Partner in same bed

**B10.** 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. | ☐ | ☐ | ☐ | ☐ |

# Your Health Care Coverage & Costs

**The following questions are related to your finances, health insurance, and health care expenses and how they relate to the medical care that you receive. We recognize that some of these questions are sensitive in nature, but these finance and care-related issues affect many survivors and their families. Learning more about them will help researchers address these issues in the future. We assure you that we will keep your answers completely confidential.**

## Health Insurance

**C1.** Do you currently have health insurance that covers outpatient care and hospital care?

- ☐ Yes
- ☐ No → **Go to Question C5, next page.**
- ☐ Canadian - provincial health insurance → **Go to Question C5, next page.**

**C2.** 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:**

**C3.** Is your household annual deductible for medical care for your insurance plan . . .

- ☐ Less than $1,300
- ☐ More than $2,600
- ☐ $1,301 to $2,600
- ☐ Don't know

**C4.** How concerned are you that you may not be able to maintain your current level of insurance coverage over the next 12 months?

- ☐ Not concerned
- ☐ Moderately concerned
- ☐ A little concerned
- ☐ Greatly concerned

Please! Do not mark below this line

## Medical Care

**C5.** In the past 12 months, did you or anyone in the house you live in have problems paying or were unable to pay any medical bills? Include bills for doctors, dentists, hospitals, therapists, medication, equipment, nursing homes or home care.

☐ Yes

☐ No → **Go to Question C7.**

☐ Don't know → **Go to Question C7.**

**C6.** Do you or anyone in the house you live in currently have medical bills that you are unable to pay at all?

☐ Yes

☐ No

**C7.** Do you or anyone in the house you live in have medical bills that are being paid off over time? This could include medical bills being paid off with a credit card, through personal loans, bill paying arrangements with hospitals or other providers, or collection agencies.

☐ Yes

☐ No

**C8.** During the past 12 months, was there a time when you needed one of the following, but did not get it because you couldn't afford it? (Check all that apply)

| | Yes | No |
|---|---|---|
| a. Any needed medical care | ☐ | ☐ |
| b. Yearly visit to your primary care doctor | ☐ | ☐ |
| c. Prescription medicine | ☐ | ☐ |
| d. Mental health care or counseling | ☐ | ☐ |
| e. Dental care | ☐ | ☐ |
| f. Eyeglasses | ☐ | ☐ |
| g. Care from a specialist | ☐ | ☐ |

**C9.** Have you or anyone in your house had to make any other kinds of financial sacrifices in the past 2 years because of debt related to medical care? (Check all that apply)

☐ Reduced spending on vacation or leisure activities

☐ Reduced spending on purchasing large items (e.g. a car)

☐ Reduced spending on basics (e.g. food and clothing)

☐ Delayed or reduced spending on home improvement

☐ Used savings set aside for other purposes (e.g. retirement, educational funds, family support)

☐ Made a change to living situation (e.g. sold, refinanced or moved to a smaller residence)

☐ Other **If Other, please specify:**

☐ No

**C10.** During the past year, about how much did you spend out-of-pocket for your medical care? Include out-of-pocket expenses for prescription drugs, co-payments, and deductibles, but do not include health insurance premiums or any costs paid by your health insurance.

$ ____,____

**C11.** Has your physical condition or medical treatment caused you financial difficulties over the past week?

☐ No difficulty

☐ A little difficulty

☐ Quite a bit of difficulty

☐ Great difficulty

**C12.** Has your physical condition or medical treatment caused you financial difficulties over the past year?

☐ No difficulty

☐ A little difficulty

☐ Quite a bit of difficulty

☐ Great difficulty

Please! Do not mark below this line

## Changes to your work schedule

**C13.** In the past 2 years, were you working for pay either full time or part time at a job or business?

- ☐ Yes
- ☐ No → Go to Question C15.

**C14.** In the past 2 years, did you ever . . .

| | Yes | No |
|---|---|---|
| a. Take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status? | ☐ | ☐ |
| b. Change to a less demanding job? | ☐ | ☐ |
| c. Change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day to day? | ☐ | ☐ |
| d. Decide not to pursue an advancement or promotion? | ☐ | ☐ |
| e. Worry that you might be forced to retire or quit work before you are ready? | ☐ | ☐ |
| f. Stay at a job in part because you were concerned about losing your health insurance? | ☐ | ☐ |

**C15.** Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

- ☐ Yes
- ☐ No
- ☐ Does not apply

## Other Worries

**C16.** If you get sick or have an accident, how worried are you that you will not be able to pay your medical bills?

- ☐ Very worried
- ☐ Somewhat worried
- ☐ Not worried

**C17.** How often in the last 12 months would you say you were worried or stressed about having enough money to pay your rent or mortgage?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know
- ☐ Prefer not to say

**C18.** How often in the last 12 months would you say you were worried or stressed about having enough money to buy nutritious meals?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know
- ☐ Prefer not to say

**C19.** How often in the last 12 months would you say you were worried or stressed about having enough money to pay household utilities such as water, gas, and electricity?

- ☐ Always
- ☐ Usually
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know
- ☐ Prefer not to say

## Who lives at home?

**C20.** 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? ☐☐

Please! Do not mark below this line

**C21.** 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

## Assets and debt

**C22.** Does anyone in the family own your home? By 'own' we mean that someone in the family living here now has their name on the title, even if mortgage or loan payments are still being made.

- ☐ Yes
- ☐ No → **Go to Question C27.**

**C23.** Who in your family owns your home? (Check all that apply)

- ☐ You
- ☐ Your spouse or significant other
- ☐ Someone else in your family

**C24.** Approximately what is the value of your home if it was sold today?

- ☐ $0-25,000
- ☐ $25,001-50,000
- ☐ $50,001-100,000
- ☐ $100,001-250,000
- ☐ $250,001-500,000
- ☐ $500,001 or more
- ☐ Don't know
- ☐ Prefer not to answer

**C25.** Are there any mortgages or other loans outstanding on this home?

- ☐ Yes
- ☐ No → **Go to Question C27.**
- ☐ Don't know → **Go to Question C27.**

**C26.** How much is currently owed on these mortgages or loans?

- ☐ $0-25,000
- ☐ $25,001-50,000
- ☐ $50,001-100,000
- ☐ $100,001-250,000
- ☐ $250,001-500,000
- ☐ $500,001 or more
- ☐ Don't know
- ☐ Prefer not to answer

**C27.** Do you or anyone in your house have other debts such as credit card balances, car loans, debts owed to medical providers, life insurance policy loans, loans from relatives and so forth?

- ☐ Yes
- ☐ No → **Go to next page.**
- ☐ Don't know → **Go to next page.**

**C28.** What is the total amount owed on this other debt?

- ☐ $0-25,000
- ☐ $25,001-50,000
- ☐ $50,001-100,000
- ☐ $100,001-250,000
- ☐ $250,001-500,000
- ☐ $500,001 or more
- ☐ Don't know
- ☐ Prefer not to answer

**C29.** Have you ever been sent to collections because of debts you were unable to pay on time or at all?

- ☐ Yes
- ☐ No

**C30.** Have you ever filed for bankruptcy because of debts you were unable to pay?

- ☐ Yes
- ☐ No → **Go to next page.**

**C31.** What was the most recent year in which you filed for bankruptcy?

| | | | |
|---|---|---|---|
| | | | |

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**

## 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

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