

## Help us improve treatment and care of patients and long-term survivors

The LTFU Study has helped improve the lives of patients and long-term survivors around the world. Your help makes this possible. For more than 25 years, survivors have shared their experiences through the LTFU survey.

Survey responses have helped doctors and scientists:

- Know more health problems caused by treatments
- Make changes in treatments to prevent health problems later in life
- Increase awareness about screening and prevention

Your responses will help change lives. Please complete this LTFU survey.

Start  
here!

Today's date:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
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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

Edit

Survey #333

Code

F

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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. 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 with minor children (<18 years old)
- ☐ Live alone
- ☐ Other

Specify

A5. Which of the following best describes your current marital status?

- ☐ Single, never married or never lived with partner as married
- ☐ Married
- ☐ Living with partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

## HEALTH AND WELL-BEING

B1. 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? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Did you have a lot of energy? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Did you feel worn out? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Did you feel tired? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
B2. Weakness or inability to move arm(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<table border="1" style="width: 40px; height: 20px;"></table>
B3. Weakness or inability to move leg(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<table border="1" style="width: 40px; height: 20px;"></table>

## Physical Activity

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

- B4. 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.

- B5. 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 B8.

☐ Yes ↴

- B6. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

Days per week

- B7. 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

- B8. 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 B11.

☐ Yes ↴

- B9. How many days per week do you do these moderate activities for at least 10 minutes at a time?

Days per week

- B10. 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

- B11. 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 B14.

☐ Yes ↴

- B12. How many days per week do you do these light activities for at least 10 minutes at a time?

Days per week

- B13. 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

- B14. Over the last 2 years, how long (if at all) has your health limited you in each of the following activities?

(Mark one box for each item.)

	Not limited at all	Limited for 3 months or less	Limited for more than 3 months
a. Walking uphill or climbing a few flights of stairs. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Eating, dressing, bathing, or using the toilet . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Continue on next page.

## HEALTH CONDITIONS

- C. Please indicate whether or not you have any of the following health conditions and the severity of the condition. If you have more than one condition in a category, pick the one that is **most severe**. Name the specific condition you are rating.

	Very severe problem requiring immediate treatment or medical care or significantly limits my daily function	Severe problem, uncontrolled with medication, or requiring multiple medications	Moderate problem, I need daily medication	Mild problem but I do not need medication	No problem
a. <b>Heart problem</b> - Examples: chest pain or angina, heart attack or myocardial infarction, abnormal heartbeat or arrhythmia, valve problems. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
b. <b>Vascular problem</b> - Examples: circulatory problems like peripheral artery disease, hypertension (high blood pressure), high cholesterol, vascular surgery/repair for arteries in neck or legs, abdominal aortic aneurysm. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
c. <b>Blood problem</b> - Examples: anemia, hypercoagulability (easy clotting), or any other blood problem that affects the spleen or lymphatic system. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
d. <b>Respiratory problem</b> - Examples: asthma, emphysema, bronchitis, pulmonary embolism (clot in lungs), lung surgery. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
e. <b>Eye, ears, nose, throat, larynx</b> - Examples: glaucoma, cataract, loss of vision, hearing loss, vertigo, dizziness, loss of smell, throat problems. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
f. <b>Stomach/digestion</b> - Examples: heartburn/reflux, swallowing problems. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
g. <b>Intestinal problems</b> - Examples: intestinal hernia, constipation, anal problems, incontinence, colon problems/surgery. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
h. <b>Liver and pancreas</b> - Examples: includes gall bladder problems/removal, impaired liver function or infection. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
i. <b>Kidney</b> - Examples: kidney infection, poor kidney function, kidney surgery. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
j. <b>Urinary</b> - Examples: stones, infection, incontinence, surgery for kidney stones. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
k. <b>Musculoskeletal</b> - Examples: arthritis, other joint problems, osteoporosis, carpal tunnel, fibromyalgia, skin problems. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
l. <b>Neurologic</b> - Examples: stroke, peripheral neuropathy, headache, cognitive decline. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
m. <b>Endocrine/metabolic</b> - Ex.: thyroid problem, obesity, diabetes, hormonal problem. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					
n. <b>Psychiatric/behavioral</b> - Ex.: depression, anxiety, alcohol or drug abuse, eating disorder. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name of Most Severe Condition: _____					

Please! Do not mark below this line

## CANCER, LEUKEMIA, OR TUMOR

D1. 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 Section E.

☐ Yes ↓

D2. What was the name of this disease?

D3. Where was it located? (Example: right upper arm, left ear)

D4. Where was this diagnosed?

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

D5. 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

## ACTIVITIES OF DAILY LIVING

E1. For each of the following, select the description that best describes you. (The word "assistance" means supervision, direction, or personal assistance.)

a. Bathing - either sponge bath; tub bath, or shower

- ☐ I receive no assistance (get in and out of tub by myself if tub is usual means of bathing)  
☐ I receive assistance in bathing only one part of the body (such as back or a leg)  
☐ I receive assistance in bathing more than one part of the body (or do not bathe)

b. Dressing - get clothes from closets and drawers - including underclothes, outer garments and using fasteners (including braces if worn)

- ☐ I get clothes and get completely dressed without assistance  
☐ I get clothes and get dressed without assistance except for assistance in tying shoes  
☐ I receive assistance in getting clothes or in getting dressed, or stay partly or completely undressed all day

c. Toileting - going to the "toilet room" for bowel and urine elimination; cleaning self after elimination, and arranging clothes

- ☐ I go to "toilet room", clean myself, and arrange my clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)  
☐ I receive assistance in going to "toilet room" or in cleaning or in arranging clothes after I am done urinating or having a bowel movement on the toilet or in use of night bedpan or commode  
☐ I am not able to go to the "toilet room" to urinate or have a bowel movement

d. Transfer

- ☐ I move in and out of my bed as well as in and out of chairs without assistance (may use object for support such as cane or walker)  
☐ I move in and out of bed or chair with assistance  
☐ I do not get out of bed

e. Urination and Bowel Movements

- ☐ I control urination and bowel movements completely by myself
- ☐ I have occasional "accidents"
- ☐ I require supervision to keep urine or bowel control; I use a catheter, or I am incontinent

f. Feeding

- ☐ I feed myself without assistance
- ☐ I feed myself except for getting assistance in cutting meat or buttering bread
- ☐ I receive assistance in feeding or am fed partly or completely by using tubes or intravenous fluids

E2. For each category, check the item description that most closely resembles your highest functional level.

a. Ability to Use Telephone

- ☐ I operate the telephone on my own - look up and dial numbers, etc.
- ☐ I dial a few well-known numbers
- ☐ I answer the telephone but do not dial
- ☐ I do not use the telephone at all

b. Shopping

- ☐ I take care of all my shopping needs
- ☐ I shop independently for small purchases
- ☐ I need to be accompanied on any shopping trip
- ☐ I am unable to shop

c. Food Preparation

- ☐ I plan, prepare and serve meals independently
- ☐ I prepare meals if supplied with ingredients
- ☐ I heat and serve prepared meals
- ☐ I need to have meals prepared and served

d. Housekeeping

- ☐ I maintain my house alone or with occasional assistance (e.g., "heavy work domestic help")
- ☐ I perform light daily tasks such as dish washing, bed making
- ☐ I perform light daily tasks but cannot maintain an acceptable level of cleanliness
- ☐ I need help with all home maintenance tasks
- ☐ I do not participate in any housekeeping tasks

e. Laundry

- ☐ I can do personal laundry completely
- ☐ I launder small items - rinse socks, stockings, etc.
- ☐ All my laundry must be done by others

f. Mode of Transportation

- ☐ I travel independently on public transportation or drive my own car
- ☐ I arrange my own travel via taxi, but I do not otherwise use public transportation
- ☐ I travel on public transportation when assisted or accompanied by another
- ☐ My travel is limited to taxi or automobile with assistance of another
- ☐ I do not travel at all

g. Responsibility for Own Medications

- ☐ I am responsible for taking medication in correct dosages at correct time
- ☐ I take responsibility if my medication is prepared in advance in separate dosages (pill box)
- ☐ I am not capable of dispensing own medication

h. Ability to Handle Finances

- ☐ I manage financial matters independently (budgets, write checks, pays rent, bills, goes to bank), collect and keep track of income
- ☐ I manage day-to-day purchases, but I need help with banking, major purchases, etc.
- ☐ I am incapable of handling money

1. Do you use a cell phone?

☐ Yes ☐ No

Skip to Question 5, then continue below to verify or update your contact information.

2. Which of the following devices do you have access to? **(Mark all that apply)**

☐ Computer or laptop ☐ Other, specify:  
☐ Tablet (iPad or similar)  
☐ Smartphone

3. Do you have access to Wi-Fi?

☐ Yes ☐ No

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

☐ Yes ☐ No ☐ My phone is not text capable

Your phone number: (    )    -

**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
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>

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
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>

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<sup>1</sup> 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 that includes but not limited to Discharge summary, X-Ray report, EKG/Echo report, History and Physical, Operative report, Pathology report, Progress and Doctor Notes, Laboratory report, consult report, Entire record. I understand that the information in my medical record may include information relating to sexually transmitted disease, acquired immunodeficiency syndrome(AIDS), or human immunodeficiency virus(HIV). It may also include information about behavioral or mental health services, and treatment for alcohol and drug abuse.
- 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 (Memphis, TN).
- 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. If not revoked before the end of the LTFU study, this authorization (permission) expires at the end of the LTFU 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 authorize the release of records for future visits or stays after the date of my signature until this authorization expires or is revoked.

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



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

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

\_\_\_\_\_  
Signature of research participant or legal guardian

\_\_\_\_\_  
Date



\_\_\_\_\_  
Printed name of legal guardian

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

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

Please! Do not mark below this line