LTFU Long-Term Follow-Up Study

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

Start here!	Today's date:	
	Your relationship:	
	Self Parent Other:	
	Please! Do not mark below this line	
	Edit Survey #334 Code P	1620313792 12/10/2024 02:29:10 PM

A1. Please respond to each item by marking one box				Alw	ays
per row.		Usually			
	Sor	netin	nes		
		arely			
a. I have trouble doing all of my regular leisure activities with others					
 b. I have trouble doing all of the family activities that I want to 					
 c. I have trouble doing all of my usual work (include work at home) 					
d. I have trouble doing all of the activities with friends that I w to do					
e. I have to limit the things I do fun with others					
f. I have to limit my regular activity with friends.					
g. I have to limit my regular far activities.	nily · · · · · □				
h. I have trouble doing all of the work that is really important me (include work at home).	to				
A2. Please respond to each question or statement by marking one box per row.		Qu	Ver lite a	y mı bit	uch
maining one box per tow.	So	mew	hat		
	A little bit				
In the <u>past 7 days</u>	Not at all				

Not at	all		
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			

PROBLEM SOLVING

B. 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 <u>PAST 6 MONTHS</u>.

Please complete all items.	<u>51 0 Mortini</u>	<u>u</u> .		
Please think about yourself as	Often	a pr	oble	m
you read these statements Sometimes a p		oble		
and mark one response on	Never a proble	m		
each line.				
1. I get upset easily				
2. It takes me longer to complete my				
3. I am disorganized		_		
4. I forget instructions easily				
5. I have problems completing my wo				
6. I have difficulty recalling things I ha				
previously learned (e.g., names, pl events, activities)	aces,	_		_
7. I get frustrated easily				
8. My mood changes frequently				П
9. I have trouble finding things in		-	ш	-
my bedroom, closet or desk				
10. I forget what I am doing in the mid				
11. I have problems getting started on				
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 activi				
17. I read slowly				
18. I am slower than others when			_	_
completing my work				
19. I have trouble solving math proble 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 activiti				
30. I have emotional outbursts for little				
31. I leave the bathroom a mess				
32. I react more emotionally to situation			_	_
than my friends				
33. I leave my room or home a mess .				

Please! Do not mark below this line

Very severe problem requiring immediate treatment or medical care **HEALTH CONDITIONS** or significantly limits my daily function Severe problem, uncontrolled with medication, or requiring multiple medications C. Please indicate whether or not you have any of the following health conditions and the severity Moderate problem, I need daily medication of the condition. If you have more than one condition in a category, pick the one that is **most** Mild problem but I do not need medication severe. Name the specific condition you are rating. No problem a. Heart problem - Examples: chest pain or angina, heart attack or myocardial infarction, abnormal heartbeat or arrhythmia, valve problems. Name of Most Severe Condition: b. Vascular problem - 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. Name of Most Severe Condition: c. Blood problem - Examples: anemia, hypercoagulability (easy clotting), or any other blood problem that affects the spleen or lymphatic system..... Name of Most Severe Condition: d. Respiratory problem - Examples: asthma, emphysema, bronchitis, pulmonary embolism (clot in lungs), lung surgery..... Name of Most Severe Condition: e. Eye, ears, nose, throat, larynx - Examples: glaucoma, cataract, loss of vision, hearing loss, vertigo, dizziness, loss of smell, throat problems. Name of Most Severe Condition: f. Stomach/digestion - Examples: heartburn/reflux, swallowing problems. Name of Most Severe Condition: _____ g. Intestinal problems - Examples: intestinal hernia, constipation, anal problems, incontinence, colon problems/surgery..... Name of Most Severe Condition: _____ h. Liver and pancreas - Examples: includes gall bladder problems/removal, impaired liver function or infection. Name of Most Severe Condition: i. **Kidney** - Examples: kidney infection, poor kidney function, kidney surgery..... Name of Most Severe Condition: j. <u>Urinary</u> - Examples: stones, infection, incontinence, surgery for kidney stones. Name of Most Severe Condition: k. **Musculoskeletal** - Examples: arthritis, other joint problems, osteoporosis, carpal tunnel, fibromyalgia, skin problems. Name of Most Severe Condition: I. Neurologic - Examples: stroke, peripheral neuropathy, headache, cognitive decline. . . . Name of Most Severe Condition: m. Endocrine/metabolic - Ex.: thyroid problem, obesity, diabetes, hormonal problem. Name of Most Severe Condition: ____ n. Psychiatric/behavioral - Ex.: depression, anxiety, alcohol or drug abuse, eating disorder. Name of Most Severe Condition:

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?



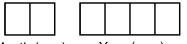
- □ Yes
- D2. What was the name of this disease?
- D3. Where was it located? (Example: right upper arm, left ear)

D4. Where was this diagnosed?

Doctor's name	
Hospital or clinic	
Address	
City, State, Zip code	9

- D5. Was this a:
 - Recurrence of original diagnosis
 - $\hfill\square$ New cancer, leukemia, tumor, or similar illness
 - Don't know

Date of Recurrence or New Diagnosis:



Month (mm)

Year (yyyy)

D6. Have you had more than one additional cancer, leukemia, tumor, or skin cancer since LastMo, LastYr?

□ No → Go to Section E, next page. □ Yes

- D7. What was the name of this disease?
- D8. Where was it located? (Example: right upper arm, left ear)

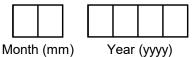
D9. Where was this diagnosed?

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

D10. Was this a:

- Recurrence of original diagnosis
- □ New cancer, leukemia, tumor, or similar illness
- Don't know

Date of Recurrence or New Diagnosis:



Please use a separate sheet of paper for additional cancers



1. Do you use a cell phone? □ Yes □ No → Skip to Question 2, the verify or update your converting or update your converting or update your converting to send/receive study- □ Yes □ No □ My phone is not text can your phone number: (□) □ □ (0,0)	ontact information of the second seco	ation.	 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
We want to make sure we can stay in touch we have your current address as:	with you. Ple		
		🗆 Mo	oving. Anticipated move date: rovide new address below if known)
Address:			
City:	State:		Zip code:
How long have you lived at your current add Please let us know if these phone numbers are		Please also	provide us with any updated phone numbers below.
Phone number Current Not current	Updated p	hone num	bers:
	Home phone	e:	Other phone number:
	Cell phone:		
Please let us know if these email addresses are	e still current.	Please als	so 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 HIPAA¹ 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.

đ	Sign	Printed name of research participant	Date of birth	Fill in dates
٠.	here	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

¹HIPAA 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!

Important new study opportunity:

To advance this critically important research, we will contact you in the next month to ask you to complete new online cognitive tests. This will be our first direct measurement of key areas of attention and memory.

The online tests will involve game-like activities that take about 20 minutes and we will send you a \$10 gift code when you are done. If you do not have a computer, don't worry, we will loan you one to use.

If you are interested in learning more, please feel free to send us an email at **LTFU@stjude.org** or call us toll free at 800-775-2167. Otherwise, we will send you more information in the near future.

Questions or comments?

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

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



This page intentionally left blank.

Please! Do not mark below this line