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

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

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

Edit ☐ Survey #334 Code ☐ P 1620313792

12/10/2024 02:29:10 PM

PROBLEM SOLVING

A1. Please respond to each item by marking one box per row.

	Never	Rarely	Sometimes	Usually	Always
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 do.	☐	☐	☐	☐	☐
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 want to do.	☐	☐	☐	☐	☐
e. I have to limit the things I do for fun with others.	☐	☐	☐	☐	☐
f. I have to limit my regular activities with friends.	☐	☐	☐	☐	☐
g. I have to limit my regular family activities.	☐	☐	☐	☐	☐
h. I have trouble doing all of the work that is really important to me (include work at home).	☐	☐	☐	☐	☐

A2. Please respond to each question or statement by marking one box per row.

In the <u>past 7 days</u>. . .

	Not at all	A little bit	Somewhat	Quite a bit	Very much
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.	☐	☐	☐	☐	☐

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. 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	☐	☐	☐

Please! Do not mark below this line

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.

	No problem	Mild problem but I do not need medication	Moderate problem, I need daily medication	Severe problem, uncontrolled with medication, or requiring multiple medications	Very severe problem requiring immediate treatment or medical care or significantly limits my daily function
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. **Urinary** - 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: _____	☐	☐	☐	☐	☐
l. **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: _____	☐	☐	☐	☐	☐

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, next page.**

☐ 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)

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

D10. 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

Please! Do not mark below this line

1. Do you use a cell phone?

☐ Yes ☐ No → **Skip to Question 2, then 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. 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 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
	☐	☐
	☐	☐
	☐	☐

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

8654313796

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 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 _____

[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

6472313792

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**

Please! Do not mark below this line

0202313797

This page intentionally left blank.