LTFU

Long-Term Follow-Up Study

www.cancer.umn.edu/ltfu

University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford
Dana-Farber Cancer Institute
Emory University
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
Seattle Children's Hospital & Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Health Care - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
Riley Hospital for Children-Indiana University
UAB/The Children's Hospital of Alabama
University of Michigan-Mott Children's Hospital
Children's Medical Center of Dallas

Our mailing address is:
Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware St. SE
Mayo Mail Code 715
Minneapolis, MN 55455

Toll-free phone number:
1-800-775-2167

e-mail: ccss@epi.umn.edu

UNIVERSITY OF MINNESOTA

Thank you for your continuing participation in the Long-Term Follow-Up Study. By sharing your experiences through time you are making a valuable contribution to the fight against childhood cancer and similar illnesses. Since it has been about two years since we last contacted you, we would like to update some information.

As you can see, the present survey is much shorter than the last two general surveys we have sent. This time, we are only asking about major medical events you may have experienced since you completed your last questionnaire. We hope you will find it less time-consuming to complete.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely

The LTFU study staff

The questions in this booklet pertain to:

Jane Doe

Person completing this questionnaire is:

[ ]

Your relationship:

☐ Self ☐ Parent ☐ Other: ____________

Today's date: [ ][ ] / [ ][ ] / [ ][ ][ ][ ]
M M D D Y Y Y Y

Please! Do not mark below this line

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A. HOSPITALIZATIONS

We are interested in any visits to the hospital for illness, surgical, or diagnostic procedures, including psychiatric hospitalization or short stays of 24 hours or less that you may have had since Month Year.

1. Have you been admitted to a hospital since Month Year?

☐ Yes ☐ No → ***Go to Section B.***

2. How many times have you been admitted to a hospital since Month Year? ☐☐

3a. What was the reason for the ***first*** hospitalization?

3b. What procedures/surgeries were performed?

3c. Where was this procedure performed?

Hospital or clinic

Address

City, State, Zipcode

Doctor's name

3d. Date of first hospitalization: ☐☐ ☐☐☐☐

Month (mm) **Year (yyyy)**

4a. What was the reason for the ***second*** hospitalization?

4b. What procedures/surgeries were performed?

4c. Where was this procedure performed?

Hospital or clinic

Address

City, State, Zipcode

Doctor's name

4d. Date of second hospitalization: ☐☐ ☐☐☐☐

Month (mm) **Year (yyyy)**

Please use a separate sheet of paper for additional hospitalizations

B. CANCER, LEUKEMIA, OR TUMOR

1. Have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse) since you last provided us information in Month Year? (Please include skin cancers.)

☐ Yes ☐ No → ***Go to next page.***

What was the name of this disease?

If this was a skin cancer, where was it located on your body?

Where was this diagnosed?

Doctor's name

Hospital or clinic

Address

City, State, Zipcode

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

HIPAA* AUTHORIZATION TO USE AND DISCLOSE
INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES

1. **Purpose.** As a research participant, I authorize Leslie L. Robison, Ph.D. and the researcher's staff to use and disclose my individual health information for the purpose of conducting the research project entitled Long-Term Follow-Up (LTFU) Study, 9104S03650.

2. **Individual Health Information to be Used or Disclosed.** My individual health information that may be used or disclosed to conduct this research includes medical records since the diagnosis of cancer or similar illness.

3. **Parties Who May Disclose My Individual Health Information.** The researcher and the researcher's staff may obtain my individual health information from:

   Hospitals:____

   Clinics:____

   Other Providers:____

   Health Plan:____,

   and from hospitals, clinics, health care providers and health plans that provide my health care during the study.

4. **Parties Who May Receive or Use My Individual Health Information.** The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Leslie L. Robison, Ph.D., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Molecular Center (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 Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study. However, my decision not to sign this authorization 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 withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, Pediatrics - University of Minnesota, 420 Delaware St SE, Mayo Mail Code 715, Minneapolis, MN 55455 to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for this research study. No further health information about me will be collected by or disclosed to the researcher for this study.

7. **Potential for Re-disclosure.** My individual health information disclosed under this authorization may be subject to re-disclosure outside the research study and no longer protected. For example, researchers in other studies could use my individual health information collected for this study without contacting me if they get approval from an Institutional Review Board (IRB) and agree to keep my information confidential.

   7A. Also, there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date.

I am the research participant or personal representative authorized to act on behalf of the participant.
I have read this information, and I will receive a copy of this authorization form after it is signed.

______________________________	______________________________
Printed name of research participant	Date of birth
______________________________	______________________________
Signature of research participant or research participant's personal representative	Date
______________________________	______________________________
Printed name of research participant's personal Representative	Description of personal representative's authority to act on behalf of the research participant

*HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

CONTINUE ON NEXT PAGE.

C. COMPUTER, INTERNET USE

1. Do you have access to the Internet?

☐ No *Go to Section D, below*

☐ Yes → Where do you use the Internet? ***(mark all that apply)***

☐ don't use it ☐ at work

☐ at home ☐ library

☐ at school ☐ other, please specify: ____________

On average, how many hours per week do you use the Internet? [|] hours per week

2. Would you be interested in completing future questionnaires over the internet if this option becomes available?............................... ☐ Yes ☐ No ☐ Maybe

D. CONTACT INFORMATION

We have your current address and phone as:

123 TESTER AVENUE
SUNNYTOWN
CA
98765
121-212-1212

Is this information . . . ☐ Correct ☐ Not correct

Please give us your correct address or location:

Address	
City	State/Province
Zip/Postal Code	Phone Number

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 at your home address.

Name	
Address	Relationship to you
City	State/Province
Zip/Postal Code	Phone Number

Please use this space for any additional comments you may have:

Please! Do not mark below this line

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