LTFU

Long-Term Follow-Up Study

St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital of Colorado
Children's Hospital of Orange County
Children's Hospital of Philadelphia
Children's Hospital of Los Angeles
Children's Hospital of Pittsburgh
Children's Hospitals & Clinics of Minnesota, Minneapolis and St. Paul
Children's Medical Center of Dallas
Children's Memorial Hospital
Children's National Medical Center
City of Hope National Medical Center
Cook Children's Hematology-Oncology Center
Dana-Farber Cancer Institute/ Children's Hospital Boston
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller Children's Hospital
Nationwide Children's Hospital
Riley Hospital for Children - Indiana University
Roswell Park Cancer Institute
Seattle Children's Hospital
St. Louis Children's Hospital
Texas Children's Hospital
Toronto Hospital for Sick Children
UAB/The Children's Hospital of Alabama
University of California at San Francisco
University of Chicago Comer Children's Hospital
University of Michigan - Mott Children's Hospital
University of Minnesota
U.T.M.D. Anderson Cancer Center

Our mailing address is:
Long-Term Follow-Up Study
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

St. Jude toll-free phone number:
1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

ltfu.stjude.org

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

Thank you for participating in the Long-Term Follow-Up study of individuals treated for cancer, leukemia, tumor or a similar illness. Your participation helps to provide us with valuable information in the fight against these serious illnesses of childhood and adolescence.

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 relate to:

Person completing this questionnaire 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

Today's date: ☐☐ / ☐☐ / ☐☐☐☐
m m d d y y y y

Please! Do not mark below this line

Survey #002

4066078304

LTFU Consent Form

This form is an informed consent statement that requires your signature if you wish to participate in the study. Please review the following three pages and sign and date at the yellow arrows.

! Watch for this symbol - it indicates that you need to do something at this point in the consent.

INFORMED CONSENT STATEMENT

LONG-TERM FOLLOW-UP STUDY

You/Your child received treatment for a childhood cancer or similar illness. We would like to invite you/your child to take part in the Long-Term Follow-Up Study (LTFU) being conducted at St. Jude Children's Research Hospital.

This consent form gives you information about the study. If you agree to take part, you can complete the consent process via the LTFU website or sign this consent document and return it in the self-addressed, stamped envelope you received. The second consent document is a copy for you to keep or you can print a copy from the website.

Before you learn about the study, it is important that you know the following:

- Whether or not you/your child take part in this study is entirely up to you.
- If you/your child decide not to be in the study, or to withdraw from the study at any time, it will not affect your/your child's relationship with St. Jude or the institution where you/your child received treatment.
- This study is being sponsored (receiving financial support to offset a portion of the costs of the study) by the National Cancer Institute.
- The principal investigator (researcher) of this study is Dr. Leslie Robison, who can be reached at 800/775-2167.
- Your/Your child's study information will be shared with researchers at St. Jude Children's Research Hospital, the LTFU Biopathology Center (Columbus, OH), LTFU Laboratory (Cincinnati, OH), LTFU Statistical Center (Seattle, WA), LTFU Follow-Up Center (Los Angeles, CA) and LTFU collaborating researchers.

Why is this study being done?

The purpose of this study is to learn about the health of persons who were treated for cancer, leukemia, tumors, or other similar illnesses as children. We are interested in studying the risk (chance) of second cancers, long-term side effects of chemotherapy and radiation therapy, and your/your child's family history of cancer. The information we collect will be used to make recommendations for the treatment and follow-up of future children who are diagnosed with cancer or a similar illness.

How many patients will take part in the study?

About 30,000 people from around the United States, who were treated as children for cancer or a similar illness, will take part in this study.

What is involved in this study?

You/Your child will complete a set of questions about your/your child's health. Answering all of the questions will take about 45 minutes. You may leave blank any questions you/your child are uncomfortable answering. The questionnaire can be completed over the internet at our website or by completing the questionnaire and returning it in the stamped, self-addressed envelope you received.

Your/Your child's treating doctor will provide researchers at St. Jude information from your/your child's hospital medical record. This information will be about your/your child's disease and about the specific treatments and procedures that you/your child received. The collected information will be entered into a computer for comparison with others who were treated as children for cancer or a similar illness. All of the information collected in this study will be kept private and participants will not be identified in any study reports.

Based on questionnaire answers and the information obtained from your/your child's medical record, you may be contacted in the future to complete additional questionnaires.

This is a long-term study of childhood survivors of cancer or similar illnesses. In the future, you will receive a shorter questionnaire in the mail every other year until the study is finished.

What are the consequences of withdrawing from this study?

You/Your child can stop taking part in this study at any time. Whether or not you/your child take part will not affect the relationship with the institution where you received treatment.

What are the risks of the study?

Protected health information you provide to researchers at St. Jude Children's Research Hospital and the University of Southern California for this study will not be given to anyone outside these institutions unless you agree. Your/Your child's information will be kept in a locked file cabinet or secure computer database.

What are the benefits of the study?

We cannot guarantee that you/your child will receive a direct benefit from taking part in this study. However, the information we collect may help us make recommendations for the treatment and follow-up of future children who are diagnosed with cancer or a similar illness.

What other options are there?

Your/Your child's participation in this study is voluntary. You/your child may choose not to take part in this study.

What about new information?

You/Your child will be told of any new information learned during the course of the study, which might cause you/your child to change your/his/her mind about staying in the study. You/your child will receive a CCSS Newsletter every six months that contains a study update and other health information that may be helpful to yourself/your child and others treated for cancer or similar illness. You/Your child have the right to learn about the results of the study. If you are interested in learning more about when and how to get the results of this research study, you may contact Dr. Leslie Robison at 901/595-3300 or Dr. Greg Armstrong, Project Director at St. Jude Children's Research Hospital, at 800/775-2167.

What about confidentiality?

Your/Your child's medical records will be kept confidential to the degree allowed by law.

St. Jude Children's Research Hospital has received a Certificate of Confidentiality from the federal government, which will help us protect the privacy of our research subjects. The Certificate protects against the involuntary release of information about subjects collected during the course of our covered studies. The researchers involved in the studies cannot be forced to disclose the identity or any information collected in the study in any legal proceedings at the federal, state, or local level, regardless of whether they are criminal, administrative, or legislative proceedings. However, the subject or the researcher may choose to voluntarily disclose the protected information under certain circumstances. For example, if the subject or his/her guardian requests the release of information in writing, the Certificate does not protect against that voluntary disclosure. Furthermore, federal agencies may review our records under limited circumstances, such as a DHHS request for information for an audit or program evaluation or an FDA request under the Food, Drug and Cosmetics Act.

Government agencies oversee research studies involving people. Your/Your child's medical records may be reviewed by the following:

- Food and Drug Administration (FDA)
- National Institutes of Health (NIH)
- Office of Human Research Protection (OHRP)
- St. Jude Children's Research Hospital Institutional Review Board, a committee that reviews the ethics and safety of research studies

By signing this consent form, you are allowing your/your child's medical records to be reviewed by these persons.

! ☐ Check this box if you do not want a summary of the information you provide through participating in the LTFU study shared with investigators at the institution where you/your child received treatment.

Where can I get more information?

If you have questions regarding this study you may contact the St. Jude Principal Investigator for this study, Dr. Leslie Robison, at 901/595-3300 or Dr. Greg Armstrong, Project Director at St. Jude Children's Research Hospital, at 800/775-2167.

You can get more information about your/your child's rights as a research participant by calling the Chairman of the St. Jude Institutional Review Board at 901/595-4357 or the St. Jude Research Participant Advocate (Ombudsman) at 901/595-4644. If you live outside of the Memphis area, you may call 1-866-583-3472 (1-866-JUDE IRB). This is a toll-free call.

IRB Approved Version: February 24, 2009
The following statement describes your/your child's rights as a research participant:

1. You/Your child may talk as much as you want with the researchers about the reasons for this study and about its risks.

2. This study may have risks that the researchers or other doctors do not know about now.

3. There will be no costs to you/your child for taking part in this research study.

4. You/your child will receive no compensation or payment of any kind for being in this study, or for any treatments, products, or any other things of value that may result from this study.

5. If you/your child choose not to enroll on this research study or withdraw from this study at any time, your decision will not affect your/your child's relationship with St. Jude or the institution where you received treatment.

6. You have the right to review the St. Jude Notice of Privacy Practices before you sign this form. That document tells how your/your child's medical information may be used or disclosed (given to someone outside the hospital). The Notice is posted at the bottom of every page on the St. Jude Internet website: www.stjude.org

7. You have the right to inspect, copy, and request changes to your/your child's protected health information that is to be used or disclosed. This consent form describes any limitations to this right, such as research information that you will not have access to until the end of the study or that will be used strictly for research purposes.

8. Your/Your child's protected health information will be disclosed to or used by the following:
   - LTFU Follow-up Center (Los Angeles, CA)
   - LTFU Laboratory (Cincinnati, OH)
   - LTFU Biopathology Center (Columbus, OH)
   - LTFU Statistical Center (Seattle, WA)

9. Your/Your child's records may also be reviewed by agencies such as the Food and Drug Administration or the National Institutes of Health, or other agencies as required by state or federal regulations.

10. Information about you that may be disclosed includes the following:
    - Complete medical record including information regarding diagnosis, illness, treatment, and information that may be recorded about previous diagnosis or treatment.
    - Information gathered as a part of this research study as explained in the informed consent/authorization.

11. Once your/your child's records are disclosed to or used by others, St. Jude Children's Research Hospital cannot guarantee that information will not be further disclosed. Also, the released information may no longer be protected by federal privacy regulations.

12. Authorization for the use and disclosure of your child's protected health information will expire when your child reaches the age of majority. At that time, the researchers will obtain your child's consent if they wish to continue to use or disclose your child's protected health information.

13. You may withdraw authorization for the disclosure or use of your/your child's records at anytime, for any reason, with the following exceptions:
    - When that information has already been disclosed or used based on your permission
    - When the information is required to maintain the integrity of the study

14. To withdraw your authorization, please complete a Revocation of Release of Authorization form. You may request this form at St. Jude Children's Research Hospital by calling the Privacy Officer at 901/595-6141. The form must be returned by mail or hand delivery to:
    HIPAA Privacy Officer
    St. Jude Children's Research Hospital
    262 Danny Thomas Place
    Memphis, TN 38105

15. If you have more questions about this study or think you have been harmed, you can call the Principal Investigator of this study, Dr. Leslie Robison at 901/595-3300.

16. You can get more information about your rights as a research participant by calling the Chairman of the Institutional Review Board at 901/595-4357 or the Research Participant Advocate (Ombudsman) at 901/595-4644. If you are outside of the Memphis area, please call 1-866/583-3472 (1-866-JUDE IRB). This is a toll-free call.

17. You received a copy of this statement.

RESEARCH PARTICIPANT STATEMENT

I have read (or have had read to me) the contents of this document and have been encouraged to ask questions. I have received answers to my questions. I give consent to take part in this research study and authorize the disclosure and use of my/my child's protected health information for the purposes of that research.

! Sign Here

_____ _____

Research Participant/Research Participant's Parent/Guardian Date

Fill in Date

Please! Do not mark below this line

This form is your permission to use or disclose medical information that we would like you to sign. It will give us permission to obtain copies of portions of your/your child's medical record that we may need to review, such as treatment history for your/your child's cancer or similar illness, or pathology reports for a subsequent cancer. You may have already signed a similar document when you filled out a previous questionnaire; however, since that release may have expired we need to ensure that your permission is kept current.

LONG-TERM FOLLOW-UP STUDY

HIPAA[1] AUTHORIZATION TO USE AND DISCLOSE INDIVIDUAL HEALTH INFORMATION FOR RESEARCH

1. Purpose. As a research participant and at my request, 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.

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 a serious illness such as a cardiac condition or a 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, and health care providers who have treated me, and health plans that have paid for my care, during this 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, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Mail Stop 735, Memphis, TN 38105 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. Once my health information is disclosed under this authorization, there is a potential that it may be re-disclosed outside this study and no longer covered by this authorization. However, the research team and the St. Jude Institutional Review Board (the committee that reviews studies to be sure that the rights and safety of study participants are protected) are very careful to protect your privacy and limit the disclosure of identifying information about you.

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.

For participants under the age of majority, this authorization will expire when they reach the age of majority (unless the participant has an appointed legal guardian who has provided authorization). A new authorization will be required when the child reaches the age of majority. For participants over the age of majority, who have an appointed legal guardian, this authorization expires at the end of the study.

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.

! Sign Here

_____ Printed name of research participant

_____ Date of birth

Fill in Date

_____ Signature of research participant or research Participant's personal representative

_____ Today's Date

_____ Printed name of research participant's personal representative

_____ Description of personal representative's 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

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:

CORRECT Grape

INCORRECT Grape

MARKING EXAMPLES

Below are some examples of how to fill out this questionnaire. Please look these over before you begin.

Example 1

1. During the past month, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No ☒ Yes

Example 2

2. Have you ever taken. . .

	No	Yes	Not sure	If yes, age at first use (years)
a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil----------	☒	☐	☐	
If yes, specify the name of the drug(s) or indicate you do not know the specific name				
b. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES, such as Zocor, Pravachol, Lipitor, Colestid (colestipol), Tricor, Lescol, Lopid (gemfibrozil), Mevacor, niacin, or Lorelco----------	☐	☒	☐	34
If yes, specify the name of the drug(s) or indicate you do not know the specific name: mevacor				

Example 3

3. When was this condition diagnosed?

04 Month (mm) 1995 Year (yyyy)

Please! Do not mark below this line

1959078302

A1. What is your date of birth?

m m / d d / y y y y

A2. What is your sex?

- ☐ Male
- ☐ Female

A3. To the nearest inch, what is your current height without shoes?

☐ feet, and ☐☐ inches

A4. To the nearest pound, what is your current weight without shoes?

☐☐☐ pounds

A5. To which one of the following groups do you belong?

- ☐ White
- ☐ Black
- ☐ American Indian or Alaskan Native
- ☐ Asian
- ☐ Pacific Islander
- ☐ Other

Specify

A5a. Are you Hispanic?

- ☐ No
- ☐ Yes

A6. Are you a twin or born of a multiple birth?

- ☐ No → *Go to Question A7.*
- ☐ Yes

A6a. If yes, which type of multiple are you?

- ☐ Identical twin
- ☐ Fraternal (non-identical) twin, same sex
- ☐ Fraternal (non-identical) twin, opposite sex
- ☐ Not sure what type of twin, same sex
- ☐ More than twin

Specify

A7. Were you adopted?

- ☐ No
- ☐ Yes

A8. How many <u>full</u> brothers and sisters (living or dead) do/did you have? Include only those brothers and sisters who have the same birth (biological) mother <u>and</u> father as you.

☐☐

A9. Concerning your current residence, do you:

- ☐ Own your residence
- ☐ Rent
- ☐ Live with parents
- ☐ Other

Specify

A10. On average, how many times per week do you use the internet?

- ☐ Never
- ☐ 1-10 times
- ☐ 11 or more times

Please! Do not mark below this line

Medical Care

The next questions are about health care received during the 2 year period between August 2009 and August 2011.

B1. Between August 2009 and August 2011, which of the following health care providers (excluding dentists) did you see or talk to for medical care? *(Mark all that apply)*

- ☐ None → *Go to Question B7.*
- ☐ Physician (including Osteopath)
- ☐ Nurse
- ☐ Chiropractor
- ☐ Physical Therapist
- ☐ Psychologist or psychiatrist
- ☐ Other

Specify

B2. Where did you receive your health care? *(Mark all that apply)*

- ☐ Doctor's office
- ☐ Oncology (cancer) center or clinic
- ☐ Other type of clinic
- ☐ Hospital
- ☐ Emergency Room or Urgent Care Center
- ☐ Long-term follow-up clinic
- ☐ Other

Specify

B3. During this 2 year period, how many times did you see a physician?

- ☐ 0 times → *Go to Question B5.*
- ☐ 1 - 2 times
- ☐ 3 - 4 times
- ☐ 5 - 6 times
- ☐ 7 - 10 times
- ☐ 11 - 20 times
- ☐ More than 20 times

B4. As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the physician indicated in question B3 (during the past 2 years) were related to this previous illness?

- ☐ 0 visits
- ☐ 1 - 2 visits
- ☐ 3 - 4 visits
- ☐ 5 - 6 visits
- ☐ 7 - 10 visits
- ☐ 11 - 20 visits
- ☐ More than 20 visits

B5. During this 2 year period, how often did you telephone a doctor's office regarding an illness or a medical condition you may have had?

- ☐ 0 times
- ☐ 1 - 2 times
- ☐ 3 - 4 times
- ☐ 5 - 6 times
- ☐ 7 - 10 times
- ☐ 11 - 20 times
- ☐ More than 20 times

B6. During this 2 year period, how many times were you admitted to any hospital?

☐☐

B7. At the present time, do you have any of the following?

	No	Yes
Persistent hair loss	☐	☐
Scarring or disfigurement of the head or neck region (including the face)	☐	☐
Scarring or disfigurement of the chest or abdominal region	☐	☐
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg)	☐	☐
Walk with a limp	☐	☐
Loss of an arm or a leg	☐	☐
Loss of an eye	☐	☐
Other	☐	☐

Specify

Please! Do not mark below this line

B8. Please indicate all medicines/drugs you took *regularly* during the two-year period between August 2009 and August 2011.

- **We are only asking about medicines/drugs which you took consistently for more than one month, or for 30 days or more in a year.**
- **Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams.**
- **Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).**

	No	Yes	Not sure	If yes, age at first use	If yes, are you currently taking any of these? No	If yes, are you currently taking any of these? Yes
1. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil	☐	☐	☐	☐☐ years	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
4. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						

Please! Do not mark below this line

B8. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between August 2009 and August 2011.

- **We are only asking about medicines/drugs which you took consistently for more than one month, or for 30 days or more in a year.**
- **Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams.**
- **Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).**

	No	Yes	Not sure	If yes, age at first use	If yes, are you currently taking any of these? No	If yes, are you currently taking any of these? Yes
6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil----------	☐	☐	☐	☐☐ years	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
10. OTHER PRESCRIBED DRUGS----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name ***and*** specify the reason the drug was prescribed.						

Please! Do not mark below this line

Medical Conditions

The next series of questions relate to medical conditions that have ever occurred in your lifetime.

Please indicate, by marking the box (either "No", "Yes", or "Not sure"), if a doctor or other health care professional has told you that you have or have had any of the following conditions. In addition, please give your approximate age when the condition first occurred. (If more than one occurrence, please give age at first occurrence.)

Because we need definite responses, it is very important to mark an answer for each question, even if you have never had that condition. Please do not leave any questions blank (unmarked).

HEARING/VISION/SPEECH

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
C1. Hearing loss requiring a hearing aid?	☐	☐	☐	☐	
C2. Deafness in both ears not completely corrected by hearing aid?	☐	☐	☐	☐	
C3. Deafness in only one ear not completely corrected by hearing aid?	☐	☐	☐	☐	
C4. Tinnitus or ringing in the ears?	☐	☐	☐	☐	
C5. Persistent dizziness or vertigo?	☐	☐	☐	☐	
C6. Hearing loss, not requiring a hearing aid?	☐	☐	☐	☐	
C7. Any other hearing problems?	☐	☐	☐	☐	

If yes, describe this problem.

C8. Legally blind in only one eye?	☐	☐	☐	☐	

If yes, do you have any sight in this eye?
☐ No ☐ Yes

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
C9. Legally blind in both eyes?	☐	☐	☐	☐	
C10. Cataracts?	☐	☐	☐	☐	
C11. Glaucoma (excess pressure in the eyeball)?	☐	☐	☐	☐	
C12. Problems with double vision?	☐	☐	☐	☐	
C13. A detached retina or any other condition of the retina?	☐	☐	☐	☐	

If yes, do you have any sight?
☐ No ☐ Yes

If yes, describe this problem.

C14. Crossed or turned eyes (strabismus)?	☐	☐	☐	☐	
C15. Lazy eye (amblyopia)?	☐	☐	☐	☐	
C16. Any other trouble seeing with one or both eyes even when wearing glasses?	☐	☐	☐	☐	
C17. Very dry eyes requiring eye drops or ointment?	☐	☐	☐	☐	
C18. Any other eye problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

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 (years)
C19. Stammering or stuttering?	☐	☐	☐	☐	
C20. Any other speech defects?	☐	☐	☐	☐	

If yes, describe this defect.

C21. Abnormal sense of taste?	☐	☐	☐	☐	
C22. Loss of taste or smell lasting for 3 months or more?	☐	☐	☐	☐	

URINARY SYSTEM

D1. Kidney stones?	☐	☐	☐	☐	
D2. REPEATED (more than 3 in any 12 month period) kidney or bladder infections?	☐	☐	☐	☐	
D3. Dialysis?	☐	☐	☐	☐	
D4. Blood in your urine?	☐	☐	☐	☐	
D5. Urinary incontinence?	☐	☐	☐	☐	
D6. Any other kind of kidney, bladder or urinary tract disorder?	☐	☐	☐	☐	

If yes, describe this disorder.

HORMONAL SYSTEMS

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 (years)
E1. An overactive thyroid gland (hyperthyroid)?	☐	☐	☐	☐	
E2. An underactive thyroid gland (hypothyroid)?	☐	☐	☐	☐	
E3. Thyroid nodules?	☐	☐	☐	☐	
E4. Swollen or enlarged thyroid gland?	☐	☐	☐	☐	
E5. Diabetes that can be controlled with diet?	☐	☐	☐	☐	
E6. Diabetes controlled with pills or tablets?	☐	☐	☐	☐	
E7. Diabetes controlled with insulin shots?	☐	☐	☐	☐	
E8. Deficiency of growth hormone?	☐	☐	☐	☐	
E9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?	☐	☐	☐	☐	
E10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?	☐	☐	☐	☐	
E11. Have you ever broken a bone?	☐	☐	☐	☐	

If yes, describe <u>all</u> occurrences.

E12. Any other hormonal problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

Males → *Go to Question F1.*

E13. **FEMALES** - Have you had a menstrual period naturally, that is, without needing hormones or medication?

☐ No ☐ Yes

If yes, age at first occurrence: ☐☐

If no, → *Go to Question E15.*

E14. **FEMALES** - At what age did you last have a menstrual period naturally, without needing hormones or medication to induce menstruation?

☐☐ **years and** ☐☐ **months old**

E15. **FEMALES** - Which one of the following statements best describes you? **(Select only one)**

☐ a. I am having regular periods and I am not taking birth control pills or female hormones (example: Premarin, estrogen)

☐ b. I am having regular periods but I am using birth control pills to prevent a pregnancy

☐ c. My menstrual periods are irregular and I am taking birth control pills or female hormones to regulate my periods

☐ d. I am currently pregnant

☐ e. I am not having menstrual periods naturally but I am taking birth control pills or female hormones

☐ f. I am not having menstrual periods naturally and I am not taking birth control pills or female hormones

☐ g. Other

If Other, please describe.

If you selected a, b, c, or d → *Go to Question F1.*

If you selected e, f, or g → *Go to Question E16.*

E16. **FEMALES** - What caused your menstrual periods to stop? **(Select only one)**

☐ Normal or early menopause

☐ Surgery (example: a hysterectomy)

☐ Pregnancy

☐ Don't know

☐ Other

If Other, please describe.

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

HEART AND CIRCULATORY SYSTEM

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
F1. Congestive heart failure or cardiomyopathy (weak heart muscle)?	☐	☐	☐	☐	☐☐
F2. A myocardial infarction (heart attack)?	☐	☐	☐	☐	☐☐
F3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor?	☐	☐	☐	☐	☐☐
F4. Coronary heart disease?	☐	☐	☐	☐	☐☐

If yes, describe this problem.

F5. Hypertension (high blood pressure) requiring medication?	☐	☐	☐	☐	☐☐

If yes, do you currently take hypertension medication?

☐ No ☐ Yes

Please! Do not mark below this line

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

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 (years)
F6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)?	☐	☐	☐	☐	
F7. Pericarditis or fluid around the heart?	☐	☐	☐	☐	
F8. Pericardial constriction (scarring or tightness of the sac around the heart)?	☐	☐	☐	☐	
F9. Stiff or leaking heart valves?	☐	☐	☐	☐	
F10. Blood clot in head, lung, arm, leg, or pelvis?	☐	☐	☐	☐	
F11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat?	☐	☐	☐	☐	
F12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	
If yes, do you currently take medication for this? ☐ No ☐ Yes					
F13. Any other heart or circulatory problems?	☐	☐	☐	☐	

If yes, describe this problem.

F14. Has anyone in your immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?

☐ No ☐ Yes

RESPIRATORY SYSTEM

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 (years)
G1. Asthma?	☐	☐	☐	☐	
G2. Chronic cough or shortness of breath for more than one month?	☐	☐	☐	☐	
G3. Have you had a need for extra oxygen?	☐	☐	☐	☐	
G4. Pneumonia, 3 or more times in the past 2 years?	☐	☐	☐	☐	
G5. Emphysema?	☐	☐	☐	☐	
G6. Lung fibrosis or "scarring" of the lung?	☐	☐	☐	☐	
G7. Problems with breathing while at rest that lasted for more than 3 months?	☐	☐	☐	☐	
G8. Any other breathing or lung problems?	☐	☐	☐	☐	

If yes, describe this problem.

It is very important that you mark an answer for each of the following questions, even if you have never had that condition.

DIGESTIVE SYSTEM

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 (years)
H1. Hepatitis?	☐	☐	☐	☐	

If yes, what type(s)? ***(Mark all that apply)***

- ☐ Hepatitis A
- ☐ Hepatitis B
- ☐ Hepatitis C
- ☐ Don't know
- ☐ Other

H2. Cirrhosis of the liver?	☐	☐	☐	☐	
H3. Any other liver trouble?	☐	☐	☐	☐	

If yes, describe.

H4. Intestinal (colon) polyps?	☐	☐	☐	☐	
H5. Fatty liver?	☐	☐	☐	☐	
H6. Esophageal strictures (narrowing of the esophagus)?	☐	☐	☐	☐	
H7. Rectal or anal fistula?	☐	☐	☐	☐	
H8. Rectal or anal stricture (narrowing or scarring)?	☐	☐	☐	☐	
H9. Any other stomach or digestive trouble?	☐	☐	☐	☐	

SURGICAL PROCEDURES

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I1. Amputation of an arm, leg, hand, foot?	☐	☐	☐	

If yes, specify (example: left hand, right foot).

I2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)?	☐	☐	☐	
I3. Other surgery of spinal cord or spine?	☐	☐	☐	

If yes, specify.

I4. Leg lengthening or shortening procedures?	☐	☐	☐	
I5. Joint replacement?	☐	☐	☐	

If yes, specify.

I6. Other bone surgery?	☐	☐	☐	

If yes, specify.

I7. Coronary artery bypass surgery?	☐	☐	☐	
I8. Pericardiectomy (stripping of the sac around the heart)?	☐	☐	☐	

Please! Do not mark below this line

It is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I9. Heart catheterization ("heart cath")?	☐	☐	☐	
I10. Angioplasty (enlarging a heart vessel using a balloon)?	☐	☐	☐	
I11. Surgery for heart valve replacement?	☐	☐	☐	
I12. Surgery for pacemaker?	☐	☐	☐	
I13. Other heart surgery?	☐	☐	☐	

If yes, specify.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I14. Surgery for intestinal obstruction (blocked intestines)?	☐	☐	☐	
I15. Colostomy or ileostomy (stool going into a bag)?	☐	☐	☐	
I16. Biopsy or removal of lump in thyroid gland?	☐	☐	☐	
I17. Removal of part or all of the thyroid gland?	☐	☐	☐	
I18. Removal of the spleen?	☐	☐	☐	
I19. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid?	☐	☐	☐	
I20. Breast biopsy?	☐	☐	☐	
I21. Breast-conserving or breast-sparing surgery (lumpectomy)?	☐	☐	☐	
I22. Mastectomy or removal of a breast?	☐	☐	☐	

If yes, was one or both breasts removed?
☐ One ☐ Both

Please indicate if you have ever had any of the following surgical procedures done.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I23. Any lung surgery?	☐	☐	☐	

If yes, specify.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I24. Periodontal (gum) surgery?	☐	☐	☐	
I25. Heart transplant?	☐	☐	☐	
I26. Lung transplant?	☐	☐	☐	
I27. Kidney transplant?	☐	☐	☐	
I28. Liver transplant?	☐	☐	☐	
I29. Bone marrow transplant?	☐	☐	☐	
I30. Other organ transplant?	☐	☐	☐	

If yes, specify transplant.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I31. Cataract surgery?	☐	☐	☐	

Males → Go to Question I35.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I32. Removal of one ovary?	☐	☐	☐	
I33. Removal of both ovaries?	☐	☐	☐	
I34. Removal of uterus?	☐	☐	☐	

Females → Go to Question I37.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I35. Removal of one testis?	☐	☐	☐	
I36. Removal of both testes?	☐	☐	☐	
I37. Any other surgery?	☐	☐	☐	

If yes, specify surgery.

Please! Do not mark below this line

Just a reminder - it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

BRAIN AND NERVOUS SYSTEM

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 (years)
J1. Problems with learning or memory?	☐	☐	☐	☐	

If yes and still present, please rate the severity of these problems:

- ☐ Mild; does not interfere with my work, school, or general life. I did not need special help in school.
- ☐ Moderate; interferes with my work, school, or general life, but I am capable of independent living. I used special help in school.
- ☐ Severe; I am significantly impaired in my school or work performance or in my general life.
- ☐ Disabling; I am unable to perform daily activities such as taking care of myself; I require full-time help or I am living in an institution for people with disabling conditions.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
J2. Epilepsy, repeated seizures, convulsions, or blackouts?	☐	☐	☐	☐	

If yes, describe this problem and list medications.

If yes, are you currently taking medication for this?
☐ No ☐ Yes

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
J3. Migraine?	☐	☐	☐	☐	

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 (years)
J4. Other severe headaches?	☐	☐	☐	☐	

If yes, list medications if required to control.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	
J5. Problems with balance, equilibrium, or ability to reach for or manipulate objects?	☐	☐	☐	☐	

If yes and still present, please rate the severity of these problems:

- ☐ Mild; does not affect walking or my daily routine.
- ☐ Moderate; it is bothersome and affects my walking but I am able to do my daily routine.
- ☐ Severe; this problem significantly affects my walking and my daily routine.
- ☐ Disabling; I require a wheelchair or cannot walk because of this problem.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	
J6. Tremors or problems with movements?	☐	☐	☐	☐	
J7. Problems chewing or swallowing solids or liquids?	☐	☐	☐	☐	
J8. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
J9. Prolonged pain in arms, legs or back?	☐	☐	☐	☐	
J10. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
J11. Weakness or inability to move arm(s)?	☐	☐	☐	☐	

Please! Do not mark below this line

Just a reminder - it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
J12. Weakness or inability to move leg(s)?	☐	☐	☐	☐	
J13. Paralysis of any kind?	☐	☐	☐	☐	
J14. Have you had a stroke?	☐	☐	☐	☐	
If yes, as a result of the stroke . . .					
a. Did the symptoms last more than 24 hours? ☐ No ☐ Yes					
b. Did it affect:					
Speech	☐	☐	☐	☐	
Only one side of the body	☐	☐	☐	☐	
Both sides of the body	☐	☐	☐	☐	
c. Did you lose consciousness? ☐ No ☐ Yes					
d. Did you have weakness or inability to move arm(s)?	☐	☐	☐	☐	
e. Did you have weakness or inability to move leg(s)?	☐	☐	☐	☐	
f. Did you have paralysis of any kind?	☐	☐	☐	☐	

If yes, describe this problem.

J15. Any other brain or nervous system problems?	☐	☐	☐	☐	

If yes, describe this problem.

Questions K1 to K18 relate to the <u>past 7 days</u>. Below is a list of problems people sometimes have. Please read each one carefully and mark the box that best describes how much that problem has <u>distressed or bothered you during the past 7 days</u> including today.

Mark only one answer for each problem and try not to skip any items.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
K1. Nervousness or shaking inside	☐	☐	☐	☐	☐
K2. Faintness or dizziness	☐	☐	☐	☐	☐
K3. Pains in heart or chest	☐	☐	☐	☐	☐
K4. Thoughts of ending your life	☐	☐	☐	☐	☐
K5. Suddenly scared for no reason	☐	☐	☐	☐	☐
K6. Feeling lonely	☐	☐	☐	☐	☐
K7. Feeling blue	☐	☐	☐	☐	☐
K8. Feeling no interest in things	☐	☐	☐	☐	☐
K9. Feeling fearful	☐	☐	☐	☐	☐
K10. Nausea or upset stomach	☐	☐	☐	☐	☐
K11. Trouble getting your breath	☐	☐	☐	☐	☐
K12. Numbness or tingling in parts of your body	☐	☐	☐	☐	☐
K13. Feeling hopeless about the future	☐	☐	☐	☐	☐
K14. Feeling weak in parts of your body	☐	☐	☐	☐	☐
K15. Feeling tense or keyed up	☐	☐	☐	☐	☐
K16. Spells of terror or panic	☐	☐	☐	☐	☐
K17. Feeling so restless you couldn't sit still	☐	☐	☐	☐	☐
K18. Feelings of worthlessness	☐	☐	☐	☐	☐

K19. Do you currently have pain as a result of your cancer or similar illness, or its treatment?

☐ No pain
☐ Small amount of pain
☐ Medium amount of pain
☐ A lot of pain
☐ Very bad, excruciating pain

K20. Do you currently have anxieties/fears as a result of your cancer or similar illness, or its treatment?

☐ No anxiety/fears
☐ Small amount of anxiety/fears
☐ Medium amount of anxiety/fears
☐ A lot of anxiety/fears
☐ Very many, extreme anxiety/fears

Please! Do not mark below this line

K21. How much bodily pain have you had during the past 4 weeks?

- ☐ None → *Go to Question L1.*
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

K22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

K23. For pain that you have had during the past 4 weeks, where has this pain been located? *(Mark all that apply)*

- ☐ Head
- ☐ Neck
- ☐ Chest
- ☐ Hands/Arms
- ☐ Abdomen
- ☐ Back
- ☐ Pelvis
- ☐ Legs/Feet
- ☐ Other _____

CANCER, LEUKEMIA, OR TUMOR

As you know, you were diagnosed with a cancer, leukemia, tumor, or other similar illness. The following questions (L1 to L10) relate to the diagnosis of another cancer, leukemia, tumor, or similar illness, or a recurrence (relapse) of your original diagnosis, which has occurred since the first one.

L1. At any time following this original diagnosis, were you diagnosed with another cancer, leukemia, tumor, or similar illness? (Include any relapse or recurrence of your original diagnosis).

- ☐ No → *Go to Question M1.*
- ☐ Yes

L2. Please write the name of this disease.

L3. Did you have treatment for this disease?

- ☐ No → *Skip L3a and go to Question L4.*
- ☐ Yes

L3a. What treatments did you receive? *(Mark all that apply)*

☐ Chemotherapy ☐ Radiation therapy ☐ Surgery

L4. Where was this diagnosed?

Hospital:
Address:
City, State/Province, Zip Code:
Doctor's Name:

L5. Was this a:

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

Date of recurrence or diagnosis:

Month ☐☐ Year ☐☐☐☐

L6. Have you had any additional cancers, leukemias, tumors, or similar illnesses after this second one?

- ☐ No → *Go to Question M1.*
- ☐ Yes

L7. Please write the name of this disease.

L8. Did you have treatment for this disease?

- ☐ No → *Skip L8a and go to Question L9.*
- ☐ Yes

L8a. What treatments did you receive? *(Mark all that apply)*

☐ Chemotherapy ☐ Radiation therapy ☐ Surgery

L9. Where was this diagnosed?

Hospital:
Address:
City, State/Province, Zip Code:
Doctor's Name:

L10. Was this a:

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

Date of recurrence or diagnosis:

Month ☐☐ Year ☐☐☐☐

Please use a separate sheet of paper for additional cancers

Please! Do not mark below this line

MARITAL STATUS

M1. What is your current living arrangement? ***(Mark 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 alone
- ☐ Other

Specify

M2. Have you ever been married or had a live-in relationship (lived as married)?

- ☐ No → ***Go to Question N1.***
- ☐ Yes

M3. Which of these possibilities best describes your current marital status?

- ☐ Married
- ☐ Living with a partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

M4. How many times have you been married or lived as married?

1	2	3	4	5	6	7	8	9+
☐	☐	☐	☐	☐	☐	☐	☐	☐

The following are questions about your first marriage or your first live-in relationship.

M5. In what year were you first married or what year did you begin living as married?

M6. What type of relationship did you have?

- ☐ Formal marriage
- ☐ Living together

M7. Are you currently in this relationship?

- ☐ No
- ☐ Yes → ***Go to Question N1.***

M8. In what year did you stop living together?

M9. How did this relationship end?

- ☐ Divorce/annulment
- ☐ Separation
- ☐ Death of your partner

The following are questions about your current or most recent marriage or live-in relationship, if this relationship is different than the relationship in questions M5-M9.

M10. In what year were you most recently married or what year did you begin living as married?

M11. What type of relationship do/did you have?

- ☐ Formal marriage
- ☐ Living together

M12. Are you currently in this relationship?

- ☐ No
- ☐ Yes → ***Go to Question N1.***

M13. In what year did you stop living together?

M14. How did this relationship end?

- ☐ Divorce/annulment
- ☐ Separation
- ☐ Death of your partner

OFFSPRING/PREGNANCY HISTORY

N1. Have you ever been sexually active (had sexual intercourse)?

- ☐ No → ***Go to Question O1.***
- ☐ Yes

N2. Are you currently sexually active?

- ☐ No
- ☐ Yes

N3. Have you or your partner had: ***(Mark all that apply)***

- ☐ A vasectomy → ***At what age?*** | | |
- ☐ A tubal ligation → ***At what age?*** | | |

Please! Do not mark below this line

N4. Are you, or your partner, currently pregnant?

☐ No

☐ Yes

N5. Was there ever a period in your life when you and a partner tried for one year or more to become pregnant, without success?

☐ No

☐ Yes

N6. Have you and a partner ever become pregnant?

☐ No → *Go to Question O1.*

☐ Yes

N7. Including live births, stillbirths, miscarriages, and abortions, how many times have you become pregnant or had a woman become pregnant by you?

☐☐ **times**

N8. Please fill in the following information for <u>each</u> of your pregnancies, or <u>each</u> time a woman has become pregnant by you, regardless of the outcome.

	Pregnancy outcome: Live birth	Stillbirth	Miscarriage	Medical abortion	Your age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
Pregnancy 1. .	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 2. .	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 3. .	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 4. .	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 5. .	☐	☐	☐	☐	☐☐	☐☐	☐☐

Please attach a separate sheet of paper if more than 5 pregnancies

HEALTH HABITS

Smoking

O1. Have you smoked at least 100 cigarettes in your entire life?

☐ No → *Go to Question O7.*

☐ Yes

O2. How old were you when you started smoking?

☐☐

O3. Do you smoke cigarettes now?

☐ No

☐ Yes

O4. On average, how many cigarettes a day do/did you smoke?

☐☐

O5. How many years, in total, have you smoked?

☐☐

O6. If you currently smoke, how many times in the past 12 months have you tried to quit smoking and not smoked for at least 24 hours?

☐☐

O7. In the past year, have you ever used any of these tobacco products? ***(Mark all that apply)***

	Never used	No longer use	Occasionally use	Regularly use
Chewing tobacco	☐	☐	☐	☐
Snuff tobacco	☐	☐	☐	☐
Pipes	☐	☐	☐	☐
Cigars	☐	☐	☐	☐

O8. For any of those that you have used or are currently using, how long have you used it?

	Less than 1 year	1 - 2 years	3 - 4 years	5 - 10 years	11+ years
Chewing tobacco	☐	☐	☐	☐	☐
Snuff tobacco	☐	☐	☐	☐	☐
Pipes	☐	☐	☐	☐	☐
Cigars	☐	☐	☐	☐	☐

Please! Do not mark below this line

Alcohol

O9. In your entire life, have you ever had at least 2 drinks of any kind of alcoholic beverage?

☐ No → *Go to Question O15.*

☐ Yes

O10. How old were you when you first started drinking alcohol?

☐☐

O11. During the last 12 months, how many alcoholic drinks did you have on a typical day when you drank alcohol?:
(If less than one per day, enter 0.)

Wine (4 oz. glass):	Beer (12 oz. can):	Mixed drink (1 shot):
☐☐	☐☐	☐☐
Glasses a day	Cans a day	Drinks a day

O12. During the last 12 months, what is the largest number of drinks you had on any single day? Was it…

☐ 24+ drinks

☐ 12-23 drinks

☐ 8-11 drinks

☐ 5-7 drinks

☐ 4 drinks

☐ 3 drinks

☐ 2 drinks

☐ 1 drink

☐ 0 drinks → *Go to Question O15.*

O13. During the last 12 months, how often did you usually have any kind of drink containing alcohol?

☐ Every day

☐ 5 to 6 times a week

☐ 3 to 4 times a week

☐ twice a week

☐ once a week

☐ 2 to 3 times a month

☐ once a month

☐ 3 to 11 times in the past year

☐ 1 or 2 times in the past year

☐ Never in the past year

O14. During the last 12 months, how often did you have 5 or more (males) or 4 or more (females) drinks containing any kind of alcohol in a single day?

☐ Every day

☐ 5 to 6 days a week

☐ 3 to 4 days a week

☐ 2 days a week

☐ 1 day a week

☐ 2 to 3 days a month

☐ 1 day a month

☐ 3 to 11 days in the past year

☐ 1 or 2 days in the past year

☐ Never in the past year

Physical Activity

O15. On how many of the past 7 days did you exercise or do sports for at least 20 minutes that made you sweat or breathe hard (e.g., dancing, jogging, basketball, etc.)

☐ 0 days ☐ 4 days

☐ 1 day ☐ 5 days

☐ 2 days ☐ 6 days

☐ 3 days ☐ 7 days

O16. Because of any impairment or health problems, do you need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around your home?

☐ No

☐ Yes

O17. Because of any impairment or health problems, do you need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

☐ No

☐ Yes

O18. Does any impairment or health problem keep you from holding a job or attending school?

☐ No

☐ Yes

O19. Do you currently have a driver's license?

☐ No

☐ Yes

Please! Do not mark below this line

O20. 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.)*

	Limited for more than 3 months	Limited for 3 months or less	Not limited at all
a. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running or participating in strenuous sports	☐	☐	☐
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling	☐	☐	☐
c. Walking uphill or climbing a few flights of stairs	☐	☐	☐
d. Bending, lifting, or stooping	☐	☐	☐
e. Walking one block	☐	☐	☐
f. Eating, dressing, bathing, or using the toilet	☐	☐	☐

Health Practices

O21. In general, would you say your health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

O22. Would you rate yourself as being:

- ☐ Completely disabled
- ☐ Severely disabled
- ☐ Moderately disabled
- ☐ Mildly disabled
- ☐ Not at all disabled

O23. Some people get a general physical examination from a doctor once in a while even though they are feeling well and have not been sick. When was the last time you had a general physical examination when you were not sick?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

O24. When was the last time you had an echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

O25. When was the last time you had a test to measure your bone strength or bone mineral density (such as a DEXA, quantitative CT scan, or ultrasound)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

O26. How long has it been since you last went to a dentist?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

Males → Go to Question P1.

O27. FEMALES - How often do you perform monthly breast self-examinations?

- ☐ Regularly (once a month)
- ☐ Occasionally
- ☐ Rarely or never

O28. FEMALES - When was the last time you had a Pap smear (test for cancer of the cervix)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

O29. FEMALES - When was the last time you had a breast examination by a doctor or a health care professional?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Don't know

O30. FEMALES - Have you ever had a mammogram?

- ☐ No
- ☐ Yes → ***Age at first mammogram*** ☐☐

FAMILY HISTORY INFORMATION

P1. Please identify YOUR FULL BROTHERS AND SISTERS (those with the same mother and father as you).

Please write in the initials of <u>all</u> of your full brothers and sisters (living or dead) in this section. (Please use a separate sheet of paper for additional siblings.)

Initials (First, Middle, Last)	Sex	Date of Birth (Mo/Day/Yr)	Status	Date of Death (Mo/Day/Yr)
	☐ Male ☐ Female		☐ Alive ☐ Dead	
	☐ Male ☐ Female		☐ Alive ☐ Dead	
	☐ Male ☐ Female		☐ Alive ☐ Dead	
	☐ Male ☐ Female		☐ Alive ☐ Dead	

GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions. Indicate "Yes" only if a physician has told you that you were born with, or have the condition.

Because we need definite responses, and questions left blank are difficult to interpret, it is very important that you mark an answer for each of the following questions, even if you have never had that condition. If you have never heard of these conditions, it is unlikely that you have had them.

Q1a. Have you ever been told by a doctor that you have. . .

	No	Yes	Not sure
a. Ataxia telangiectasia.	☐	☐	☐
b. Beckwith-Wiedemann syndrome	☐	☐	☐
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2)	☐	☐	☐
d. Bloom's syndrome	☐	☐	☐
e. Down syndrome	☐	☐	☐
f. Klinefelter's syndrome.	☐	☐	☐
g. Fanconi's anemia.	☐	☐	☐
h. Multiple exostoses	☐	☐	☐
i. Familial adenomatous polyposis (FAP or Gardner syndrome).	☐	☐	☐
j. Neurofibromatosis (Type 1).	☐	☐	☐
k. Nevoid basal cell carcinoma syndrome .	☐	☐	☐
l. Turner's syndrome.	☐	☐	☐
m. Von Hippel-Lindau syndrome.	☐	☐	☐
n. Wiskott-Aldrich syndrome.	☐	☐	☐
o. Xeroderma pigmentosum.	☐	☐	☐
p. Any other genetic disorder	☐	☐	☐

If yes, describe this disorder.

Q1b. Has anyone in your immediate family (blood relatives only) ever had any of the above conditions? *(Mark all that apply)*

What conditions?

- ☐ Mother →
- ☐ Father →
- ☐ Full brother →
- ☐ Full sister →
- ☐ Son →
- ☐ Daughter →

Please! Do not mark below this line

CONDITIONS PRESENT AT BIRTH

It is very important that you mark an answer for each of the following questions even if you have never had the condition.

Q2. Have you ever had genetic counseling for cancer risk?

☐ No

☐ Yes

Q3a. To the best of your knowledge, were you born with. . .

	No	Yes	Not sure
a. Cleft lip or palate	☐	☐	☐
b. Club foot	☐	☐	☐
c. Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime)	☐	☐	☐
d. Deafness or impaired hearing at birth	☐	☐	☐
e. Blindness or difficulty seeing at birth	☐	☐	☐
f. Eyes different colors or missing an iris (the colored part of the eye)	☐	☐	☐
g. Hydrocephalus (excessive water around or within the brain)	☐	☐	☐
h. Spina bifida or other neural tube defect	☐	☐	☐
i. Unusually small head (microcephaly)	☐	☐	☐
j. Unequal sized limbs (hemihypertrophy)	☐	☐	☐
k. Extra fingers, deformed chest, shortened limbs or any other skeletal abnormality	☐	☐	☐
l. Hole in the heart or other congenital heart defect	☐	☐	☐

If other, please specify.

m. Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines)	☐	☐	☐
n. Any kidney, bladder, or genital abnormalities	☐	☐	☐
o. Undescended testes	☐	☐	☐
p. Any other birth defects	☐	☐	☐

If other, please specify.

Q3b. Has anyone in your immediate family (blood relatives only) ever had any of the conditions in Question Q3a? *(Mark all that apply)*

What conditions?

☐ Mother →

☐ Father →

☐ Full brother →

☐ Full sister →

☐ Son →

☐ Daughter →

Q4. Has anyone in your immediate family (blood relatives only) ever had cancer? *(Mark all that apply)*

What types?

☐ Mother →

☐ Father →

☐ Full brother →

☐ Full sister →

☐ Son →

☐ Daughter →

Continue on next page.

SCHOOL HISTORY

R1. What is the highest grade or level of schooling that you have completed?

- ☐ 1 - 8 years (grade school)
- ☐ 9 - 12 years (high school), but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate level
- ☐ Other

Specify

R2. If you have completed high school, did you receive a regular high school diploma or did you receive a high school equivalency certificate, also called a GED?

- ☐ High school diploma
- ☐ GED

R3. In elementary, junior, or high school were you ever in any of the following programs? ***(Mark all that apply)***

	No	Yes	Not sure
Learning disabled or special education program?	☐	☐	☐
If yes, were you in the program because of. . .			
a. Missed school.	☐	☐	☐
b. Low scores on tests.	☐	☐	☐
c. Problems learning or concentrating.	☐	☐	☐
d. Emotional or behavioral problems.	☐	☐	☐
Advanced placement or talented program?	☐	☐	☐
Homebound education for at least one school year?	☐	☐	☐

R4. If you were in a learning disabled or special education program, what grades were you in at that time? ***(Mark all that apply)***

☐ K	☐ 5th	☐ 9th
☐ 1st	☐ 6th	☐ 10th
☐ 2nd	☐ 7th	☐ 11th
☐ 3rd	☐ 8th	☐ 12th
☐ 4th		

EMPLOYMENT HISTORY

S1. Have you ever had a job?

- ☐ No → ***Go to Question S4.***
- ☐ Yes

S2. What is your current employment status? Include unpaid work in the family business or farm. ***(Mark all that apply)***

- ☐ Not currently working → ***Go to Question S4.***
- ☐ Working full-time (30 or more hours per week)
- ☐ Working part-time (less than 30 hours per week)
- ☐ Caring for home or family (not seeking paid work)
- ☐ Unemployed and looking for work
- ☐ Unable to work due to illness or disability
- ☐ Retired
- ☐ Student
- ☐ Other

Specify.

S3. The following questions are about your present occupation. Please write your job title and brief details of what you do. If you have more than one job, please give the title of <u>your main job (please give only one)</u>:

S3a. Main job title:

S3b. Please briefly describe your primary job tasks:

S4. Have you ever applied for entry into the following services?

	No	Yes
Military (Army, Navy, etc.)	☐	☐
Police Department	☐	☐
Fire Department.	☐	☐

S5. Have you ever <u>not</u> gotten a job or into military service because of your previous medical history?

Civilian job	☐	☐
Military (Army, Navy, etc.)	☐	☐
Police Department	☐	☐
Fire Department.	☐	☐

Please! Do not mark below this line

INCOME

T1. Over the last year, what was the total income of the household you live in?

- ☐ Less than $19,999
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999
- ☐ Over $100,000
- ☐ Don't know

T2. During the past year, how many people in this household were supported on this income?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9 or more

T3. Over the last year, what was your personal income?

- ☐ None
- ☐ Less than $19,999
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999
- ☐ Over $100,000

INSURANCE

U1. Have you ever had difficulty obtaining health insurance because of your health history?

- ☐ No
- ☐ Yes

U2. Do you currently have health insurance coverage?

- ☐ Canadian resident → *Go to Question U4.*
- ☐ No → *Go to Question U4.*
- ☐ Yes

U3. How is this insurance provided? *(Mark all that apply)*

- ☐ Through your place of employment
- ☐ Through your spouse's or parent's policy
- ☐ Through a policy you have purchased yourself
- ☐ Medicaid or other public assistance program
- ☐ Medicare
- ☐ Military dependant/Veteran's benefits (CHAMPUS)
- ☐ Other

Specify.

U3a. Does this health insurance plan have any exclusions or restrictions because of your health history?

- ☐ Don't know
- ☐ No
- ☐ Yes

Specify.

U3b. Is there an extra premium charge on your health insurance policy because of your health history?

- ☐ Don't know
- ☐ No
- ☐ Yes

U4. Have you ever had difficulty obtaining life insurance because of your health history?

- ☐ No
- ☐ Yes
- ☐ Never tried to obtain life insurance

U5. Do you currently have life insurance coverage?

- ☐ No
- ☐ Yes

OTHER ISSUES

Please rate how concerned you are about the following:

	Very concerned	Somewhat concerned	Concerned	Not very concerned	Not at all concerned
V1. Your future health	☐	☐	☐	☐	☐
V2. Your ability to have children	☐	☐	☐	☐	☐
V3. Developing a cancer	☐	☐	☐	☐	☐
V4. Your ability to get health insurance.	☐	☐	☐	☐	☐
V5. Your ability to get life insurance	☐	☐	☐	☐	☐
V6. Any other issues	☐	☐	☐	☐	☐

Please specify.

Please! Do not mark below this line

For our future planning, what type of information or help do you think should be available to survivors of childhood cancer, leukemia, tumor, or similar illnesses?

Attach additional pages, if necessary.

We have your current address and phone as:

Is this information correct, or are you planning on moving in the next 6 months?

☐ Correct ☐ Not correct ☐ Moving

Do you have an email address we could use to contact you?

☐ No ☐ Yes

Your Email Address

Please give us your correct address or location (if different from above) and also cell phone number:

Address		
City	State	
Zip Code	Home Phone Number	Cell 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
Zip Code	Phone Number

When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

LONG-TERM FOLLOW-UP STUDY
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

Thank you!

Please! Do not mark below this line

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