LTFU

Long-Term Follow-Up Study

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

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

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 child's 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:

☐ Parent ☐ Other: _____

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

Please! Do not mark below this line

Survey #010

9129630998

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 your child 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. Has your child ever taken. . .

	No	Yes	Not sure	If yes, age at first use
a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil----------	☒	☐	☐	years
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

A1. What is your child's date of birth?

m m / d d / y y y y

A2. What is his/her sex?

- ☐ Male
- ☐ Female

A3. To the nearest inch, what is his/her current height without shoes?

☐ feet, and ☐☐ inches

A4. To the nearest pound, what is his/her current weight without shoes?

☐☐☐ pounds

A5. To which one of the following groups does he/she belong?

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

Specify

A5a. Is he/she Hispanic?

- ☐ No
- ☐ Yes

A6. Is he/she a twin or born of a multiple birth?

- ☐ No → *Go to Question A7.*
- ☐ Yes

A6a. If yes, which type of multiple is he/she?

- ☐ 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. Was this child adopted?

- ☐ No
- ☐ Yes

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

☐☐

A9. Concerning your child's current residence, does he/she:

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

Specify

A10. On average, how many times per week does your child 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 by your child 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 your child 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 your child receive his/her 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 your child 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 your child was 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 your child 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 was he/she admitted to any hospital?

☐☐

B7. At the present time, does your child 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 your child took *regularly* during the two-year period between August 2009 and August 2011.

- **We are only asking about medicines/drugs which he/she 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 were bought without a prescription (over-the-counter drugs).**

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking any of these? No	If yes, is he/she 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						

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

- We are only asking about medicines/drugs which he/she 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 were bought without a prescription (over-the-counter drugs).

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking any of these? No	If yes, is he/she 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 child's 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 your child has or has had any of the following conditions. In addition, please give your child's 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 your child has 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 your child has, or has 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.

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

If yes, does he/she have any sight in this eye?
☐ No ☐ Yes

Have you ever been told by a doctor or other health care professional that your child has, or has 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, does he/she have any sight?
☐ No ☐ Yes

If yes, describe this problem.

	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)
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 your child has never had that condition.

Have you ever been told by a doctor or other health care professional that your child has, or has 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 his/her 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 your child has, or has 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. Has your child received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?	☐	☐	☐	☐	
E10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?	☐	☐	☐	☐	
E11. Has your child 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

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

HEART AND CIRCULATORY SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has 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?	☐	☐	☐	☐	
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?	☐	☐	☐	☐	

If yes, does he/she currently take hypertension medication?
☐ No ☐ Yes

Have you ever been told by a doctor or other health care professional that your child has, or has 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)
F12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	

If yes, does he/she currently take medication for this?
☐ No ☐ Yes

F13. Any other heart or circulatory problems?	☐	☐	☐	☐	

If yes, describe this problem.

F14. Has anyone in your child's immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?
☐ No ☐ Yes

RESPIRATORY SYSTEM

G1. Asthma?	☐	☐	☐	☐	
G2. Chronic cough or shortness of breath for more than one month?	☐	☐	☐	☐	
G3. Has your child 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.

Please! Do not mark below this line

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

DIGESTIVE SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has 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)
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 your child has 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 your child has never had that condition.

Please indicate if your child has 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 your child has 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 your child has never had that condition.

BRAIN AND NERVOUS SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has 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 child's work, school, or general life. He/she does/did not need special help in school.
- ☐ Moderate; interferes with my child's work, school, or general life, but he/she is capable of independent living. He/she uses/used special help in school.
- ☐ Severe; My child is significantly impaired in his/her school or work performance or in his/her general life.
- ☐ Disabling; My child is unable to perform daily activities such as taking care of himself/herself; My child requires full-time help or he/she is living in an institution for people with disabling conditions.

J2. Epilepsy, repeated seizures, convulsions, or blackouts?	☐	☐	☐	☐	

If yes, describe this problem and list medications.

If yes, is your child currently taking medication for this?
☐ No ☐ Yes

J3. Migraine?	☐	☐	☐	☐	

Have you ever been told by a doctor or other health care professional that your child has, or has 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.

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 daily routine.
- ☐ Moderate; it is bothersome and affects walking but my child is able to do daily routine.
- ☐ Severe; this problem significantly affects my child's walking and daily routine.
- ☐ Disabling; My child requires a wheelchair or cannot walk because of this problem.

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)?	☐	☐	☐	☐	

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

Have you ever been told by a doctor or other health care professional that your child has, or has 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. Has your child 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 your child lose consciousness? ☐ No ☐ Yes					
d. Did he/she have weakness or inability to move arm(s)?	☐	☐	☐	☐	
e. Did he/she have weakness or inability to move leg(s)?	☐	☐	☐	☐	
f. Did he/she have paralysis of any kind?	☐	☐	☐	☐	

If yes, describe this problem.

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

If yes, describe this problem.

SOCIAL FUNCTIONING

K1. About how many close friends does your child have?

- ☐ 0 → *Go to Question K3.*
- ☐ 1
- ☐ 2 or 3
- ☐ 4 or more

K2. About how many times a week does your child do things with close friends?

- ☐ Less than 1
- ☐ 1 or 2
- ☐ 3 or more

K3. Compared to other children of his/her age, how well does your child . . .

	Worse	About Same	Better
a. Get along with his/her brothers and sisters?	☐	☐	☐
b. Get along with other children?	☐	☐	☐
c. Behave with his/her parents?	☐	☐	☐
d. Play and work by himself/herself?	☐	☐	☐

K4. How well do the following statements describe your child's behavior?

	Often True	Sometimes True	Not True
a. Has sudden changes in mood or feelings	☐	☐	☐
b. Feel or complains that no one loves him/her	☐	☐	☐
c. Is rather high strung, tense, or nervous	☐	☐	☐
d. Cheats or tells lies	☐	☐	☐
e. Is too fearful or anxious	☐	☐	☐
f. Argues too much	☐	☐	☐
g. Has difficulty concentrating, cannot pay attention for long	☐	☐	☐
h. Is easily confused, seems to be in a fog	☐	☐	☐
i. Bullies, or is cruel or mean to others	☐	☐	☐
j. Is disobedient at home	☐	☐	☐
k. Is disobedient at school	☐	☐	☐
l. Does not seem to feel sorry after he/she misbehaves	☐	☐	☐

K4. (Cont.) How well do the following statements describe your child's behavior?

	Often True	Sometimes True	Not True
m. Has trouble getting along with other children	☐	☐	☐
n. Has trouble getting along with teachers	☐	☐	☐
o. Is impulsive, or acts without thinking.	☐	☐	☐
p. Feels worthless or inferior	☐	☐	☐
q. Is not liked by other children	☐	☐	☐
r. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions	☐	☐	☐
s. Is restless or overly active, cannot sit still	☐	☐	☐
t. Is stubborn, sullen, or irritable	☐	☐	☐
u. Has a very strong temper and loses it easily	☐	☐	☐
v. Is unhappy, sad or depressed	☐	☐	☐
w. Is withdrawn, does not get involved with others	☐	☐	☐

If child is 12 years of age or older → *Go to Question K6.*

K5. FOR CHILDREN UNDER 12 YEARS OF AGE

	Often True	Sometimes True	Not True
a. Breaks things on purpose, deliberately destroys his/her own things	☐	☐	☐
b. Clings to adults	☐	☐	☐
c. Cries too much	☐	☐	☐
d. Demands a lot of attention	☐	☐	☐
e. Is too dependent on others	☐	☐	☐

If child is under 12 years of age → *Go to Question K7.*

K6. FOR CHILDREN 12 YEARS OF AGE OR OLDER

	Often True	Sometimes True	Not True
a. Feels others are out to get him/her	☐	☐	☐
b. Hangs around with kids who get into trouble.	☐	☐	☐
c. Is secretive, keeps things to himself/herself	☐	☐	☐
d. Worries too much	☐	☐	☐

K7. Does your child currently have pain as a result of his/her 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

K8. Does your child currently have anxieties/fears as a result of his/her 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

K9. How much bodily pain has your child had during the past 4 weeks?

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

K10. During the past 4 weeks, how much did pain interfere with your child's normal work (including both work outside the home and housework)?

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

K11. For pain that your child has had during the past 4 weeks, where has this pain been located? ***(Mark all that apply)***

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

Specify

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMORS

As you know, your child was 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 his/her original diagnosis, which has occurred since the first one.

L1. At any time following this original diagnosis, was your child diagnosed with another cancer, leukemia, tumor, or similar illness? (Include any relapse or recurrence of his/her original diagnosis).

☐ No → *Go to Question M1.*

☐ Yes

L2. Please write the name of this disease.

L3. Did he/she have treatment for this disease?

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

☐ Yes → **L3a. What treatments did he/she 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 child's original diagnosis
- ☐ New cancer, leukemia, tumor, or similar illness
- ☐ Don't know

Date of recurrence or diagnosis:

Month **Year**

L6. Has your child 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 he/she have treatment for this disease?

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

☐ Yes → **L8a. What treatments did he/she 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 child's 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 child's current living arrangement? *(Mark all that apply)*

- ☐ Lives with spouse/partner
- ☐ Lives with parent(s)
- ☐ Lives with roommate(s)
- ☐ Lives with brother(s) and/or sister(s)
- ☐ Lives with other relative(s) (not including minor children)
- ☐ Lives alone
- ☐ Other

Specify

M2. Has your child 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 his/her <u>current</u> marital status?

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

M4. How many times has he/she been married or lived as married?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9+

OFFSPRING/PREGNANCY HISTORY

N1. To your knowledge, has your child ever been sexually active (had sexual intercourse)?

- ☐ Don't know
- ☐ No → ***Go to Question O1.***
- ☐ Yes

N2. Is he/she currently sexually active?

- ☐ Don't know
- ☐ No
- ☐ Yes

N3. Has your child or his/her partner had: *(Mark all that apply)*

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

N4. Is your daughter currently pregnant, or does your son currently have a woman pregnant by him?

- ☐ Don't know
- ☐ No
- ☐ Yes

N5. Was there ever a period in your child's life when he/she and a partner tried for one year or more to become pregnant, without success?

- ☐ Don't know
- ☐ No
- ☐ Yes

N6. Has your daughter ever become pregnant, or has your son ever had a woman become pregnant by him?

- ☐ Don't know
- ☐ No → ***Go to Question O1.***
- ☐ Yes

N7. Including live births, stillbirths, miscarriages, and abortions, how many times has your daughter become pregnant or has your son had a woman become pregnant by him?

☐☐ **times**

Please! Do not mark below this line

N8. Please fill in the following information for each of your daughter's pregnancies, or each time a woman has become pregnant by your son, regardless of the outcome.

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

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

HEALTH HABITS

Physical Activity

O1. On how many of the past 7 days did your child exercise or do sports for at least 20 minutes that made him/her sweat or breathe hard (e.g., dancing, jogging, basketball, etc.)?

- ☐ 0 days
- ☐ 1 day
- ☐ 2 days
- ☐ 3 days
- ☐ 4 days
- ☐ 5 days
- ☐ 6 days
- ☐ 7 days

O2. Because of any impairment or health problems, does your child need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around their home?

- ☐ No
- ☐ Yes

O3. Because of any impairment or health problems, does your child 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

O4. Does any impairment or health problem keep your child from holding a job or attending school?

- ☐ No
- ☐ Yes

O5. Does he/she currently have a driver's license?

- ☐ No
- ☐ Yes

O6. Over the last 2 years, how long (if at all) has your child's health limited him/her 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 he/she can do, like lifting heavy objects, running or participating in strenuous sports.	☐	☐	☐
b. The kinds or amounts of moderate activities he/she 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

O7. In general, would you say your child's health is:

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

O8. Would you rate your child as being:

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

O9. 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 your child had a general physical examination when he/she was 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

O10. When was the last time your child 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

O11. When was the last time your child had a test to measure his/her 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

O12. How long has it been since your child 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

FAMILY HISTORY INFORMATION

P1. Please identify YOUR CHILD'S FULL BROTHERS AND SISTERS (those with the same mother and father).

Please write in the initials of all of your child's 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 your child was born with, or has 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 your child has never had that condition. If you have never heard of these conditions, it is unlikely that your child has had them.

Q1a. Have you ever been told by a doctor that your child has. . .

	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. Polyposis coli (Gardner's 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 child's immediate family (blood relatives only) ever had any of the above conditions? *(Mark all that apply)*

My child's . . .	***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 your child has never had the condition.

Q2. Has your child ever had genetic counseling for cancer risk?

☐ No

☐ Yes

Q3a. To the best of your knowledge, was your child 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 child's immediate family (blood relatives only) ever had any of the conditions in Question Q3a? *(Mark all that apply)*

My child's . . .	***What conditions?***
☐ Mother →	
☐ Father →	
☐ Full brother →	
☐ Full sister →	
☐ Son →	
☐ Daughter →	

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

My child's . . .	***What types?***
☐ Mother →	
☐ Father →	
☐ Full brother →	
☐ Full sister →	
☐ Son →	
☐ Daughter →	

Please! Do not mark below this line

SCHOOL HISTORY

R1. What is the highest grade or level of schooling that your child has 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 your child has completed high school, did he/she receive a regular high school diploma or did he/she receive a high school equivalency certificate, also called a GED?

- ☐ High school diploma
- ☐ GED

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

	No	Yes	Not sure
Learning disabled or special education program?	☐	☐	☐
If yes, was he/she 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 your child was in a learning disabled or special education program, what grades was he/she in at that time? ***(Mark all that apply)***

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

EMPLOYMENT HISTORY

S1. Has your child ever had a job?

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

S2. What is his/her 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.

Continue on next page.

S3. The following questions are about your child's present occupation. Please write his/her job title and brief details of what he/she does. If he/she has more than one job, please give the title of your child's main job (please give only one):

S3a. Main job title:

S3b. Please briefly describe your child's primary job tasks:

S4. Has your child ever applied for entry into the following services?

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

S5. Has your child ever not gotten a job or into military service because of his/her previous medical history?

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

INCOME

T1. Over the last year, what was the total income of the household your child lives in?

- ☐ Less than $19,999
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999
- ☐ Over $100,000

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

Continue on next page.

Please! Do not mark below this line

INSURANCE

U1. Have you ever had difficulty obtaining health insurance for your child because of his/her health history?

☐ No

☐ Yes

U2. Does your child 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 parent's place of employment

☐ Through parent's policy

☐ Through a policy you have purchased for your child

☐ 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 child's health history?

☐ Don't know

☐ No

☐ Yes

Specify.

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

☐ Don't know

☐ No

☐ Yes

U4. Have you ever had difficulty obtaining life insurance for your child because of his/her health history?

☐ No

☐ Yes

☐ Never tried to obtain life insurance

U5. Does your child 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 child's future health	☐	☐	☐	☐	☐
V2. Your child's ability to have children .	☐	☐	☐	☐	☐
V3. Your child developing a cancer . . .	☐	☐	☐	☐	☐
V4. Your ability to get health insurance for your child	☐	☐	☐	☐	☐
V5. Your ability to get life insurance for your child	☐	☐	☐	☐	☐
V6. Any other issues	☐	☐	☐	☐	☐

Please specify.

Continue on next page.

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 child's 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 child's correct address or location (if different from above) and cell phone number if applicable:

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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