

# 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

lftu.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 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:

		/			/				
<b>m</b>	<b>m</b>		<b>d</b>	<b>d</b>		<b>y</b>	<b>y</b>	<b>y</b>	<b>y</b>

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.

**Please! Do not mark below this line**

### 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.

**SUMMARY OF RESEARCH AND PRIVACY RIGHTS  
NON-THERAPEUTIC AND MINIMAL RISK RESEARCH**

**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](http://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.



\_\_\_\_\_

Research Participant/Research Participant's Parent/Guardian

\_\_\_\_\_

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<sup>1</sup> 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.

			
	Printed name of research participant	Date of birth	
	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		

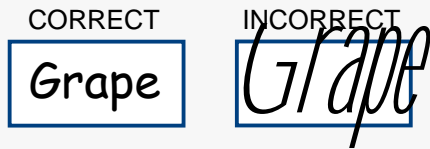
<sup>1</sup> HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

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:



### 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

	Not sure		If yes, age at first use
	Yes		
No			↓ years
<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	□ □
	<input type="checkbox"/>	<input checked="" type="checkbox"/>	3 4

#### Example 2

2. Have you ever taken. . .

- 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-----

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)

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 full brothers and sisters (living or dead) do/did you have? Include only those brothers and sisters who have the same birth (biological) mother and 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

# 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. . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Scarring or disfigurement of the head or neck region (including the face). . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Scarring or disfigurement of the chest or abdominal region. . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg). . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Walk with a limp. . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Loss of an arm or a leg . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Loss of an eye . . . . .	<input type="checkbox"/>	<input type="checkbox"/>
Other. . . . .	<input type="checkbox"/>	<input type="checkbox"/>

Specify



**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).

If yes, age at first use

If yes, are you currently taking any of these?

1. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil -----

	Not sure			
	Yes			Yes
No			years	No
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>

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-----

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
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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-----

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
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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)-----

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
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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-----

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="checkbox"/>
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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 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).

6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

Not sure

Yes

No

If yes, age at first use

years

If yes, are you currently taking any of these?

Yes

No

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

years

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

years

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

years

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.

years

# 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? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C2. Deafness in both ears not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C3. Deafness in only one ear not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C4. Tinnitus or ringing in the ears? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C5. Persistent dizziness or vertigo? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C6. Hearing loss, not requiring a hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C7. Any other hearing problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*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? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C10. Cataracts? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C11. Glaucoma (excess pressure in the eyeball)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C12. Problems with double vision? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C13. A detached retina or any other condition of the retina? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

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

*If yes, describe this problem.*

C14. Crossed or turned eyes (strabismus)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C15. Lazy eye (amblyopia)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C16. Any other trouble seeing with one or both eyes even when wearing glasses? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C17. Very dry eyes requiring eye drops or ointment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C18. Any other eye problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*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, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
C19. Stammering or stuttering? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C20. Any other speech defects? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe this defect.*

C21. Abnormal sense of taste? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
C22. Loss of taste or smell lasting for 3 months or more? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

## URINARY SYSTEM

D1. Kidney stones? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D2. REPEATED (more than 3 in any 12 month period) kidney or bladder infections? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D3. Dialysis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D4. Blood in your urine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D5. Urinary incontinence? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
D6. Any other kind of kidney, bladder or urinary tract disorder? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*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, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
E1. An overactive thyroid gland (hyperthyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E2. An underactive thyroid gland (hypothyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E3. Thyroid nodules? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E4. Swollen or enlarged thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E5. Diabetes that can be controlled with diet? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E6. Diabetes controlled with pills or tablets? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E7. Diabetes controlled with insulin shots? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E8. Deficiency of growth hormone? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
E11. Have you ever broken a bone? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe all occurrences.*

E12. Any other hormonal problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
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*If yes, describe this problem.*

**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)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
F2. A myocardial infarction (heart attack)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
F3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
F4. Coronary heart disease? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

*If yes, describe this problem.*

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

*If yes, do you currently take hypertension medication?*

No  Yes

**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, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
F6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F7. Pericarditis or fluid around the heart? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F8. Pericardial constriction (scarring or tightness of the sac around the heart)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F9. Stiff or leaking heart valves? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F10. Blood clot in head, lung, arm, leg, or pelvis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
F12. High cholesterol (or triglyceride) requiring prescription medication? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
<div style="border: 1px solid black; padding: 5px;"> <p><b>If yes, do you currently take medication for this?</b></p> <p><input type="checkbox"/> No    <input type="checkbox"/> Yes</p> </div>					
F13. Any other heart or circulatory problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**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, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
G1. Asthma? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G2. Chronic cough or shortness of breath for more than one month? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G3. Have you had a need for extra oxygen? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G4. Pneumonia, 3 or more times in the past 2 years? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G5. Emphysema? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G6. Lung fibrosis or "scarring" of the lung? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G7. Problems with breathing while at rest that lasted for more than 3 months? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
G8. Any other breathing or lung problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**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, 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? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, what type(s)? (Mark all that apply)</b>					
<input type="checkbox"/> Hepatitis A					
<input type="checkbox"/> Hepatitis B					
<input type="checkbox"/> Hepatitis C					
<input type="checkbox"/> Don't know					
<input type="checkbox"/> Other					
H2. Cirrhosis of the liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H3. Any other liver trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, describe.</b>					
H4. Intestinal (colon) polyps? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H5. Fatty liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H6. Esophageal strictures (narrowing of the esophagus)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H7. Rectal or anal fistula? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H8. Rectal or anal stricture (narrowing or scarring)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H9. Any other stomach or digestive trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

## 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? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, specify (example: left hand, right foot).</b>				
I2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
I3. Other surgery of spinal cord or spine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, specify.</b>				
I4. Leg lengthening or shortening procedures? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
I5. Joint replacement? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, specify.</b>				
I6. Other bone surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, specify.</b>				
I7. Coronary artery bypass surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
I8. Pericardiectomy (stripping of the sac around the heart)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**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<br>years |
|--|--------------------------|--------------------------|--------------------------|--|
| I9. Heart catheterization ("heart cath")? .....                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I10. Angioplasty (enlarging a heart vessel using a balloon)? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I11. Surgery for heart valve replacement? .....                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I12. Surgery for pacemaker? .....                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I13. Other heart surgery? .....                                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |

**If yes, specify.**

- |  |                          |                          |                          |                      |
|--|--------------------------|--------------------------|--------------------------|----------------------|
| I14. Surgery for intestinal obstruction (blocked intestines)? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I15. Colostomy or ileostomy (stool going into a bag)? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I16. Biopsy or removal of lump in thyroid gland? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I17. Removal of part or all of the thyroid gland? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I18. Removal of the spleen? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I19. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I20. Breast biopsy? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I21. Breast-conserving or breast-sparing surgery (lumpectomy)? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I22. Mastectomy or removal of a breast? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |

**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<br>years |
|------------------------------------|--------------------------|--------------------------|--------------------------|--|
| I23. Any lung surgery? .....       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| <b>If yes, specify.</b>            |                          |                          |                          |  |
| I24. Periodontal (gum) surgery? .  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I25. Heart transplant? .....       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I26. Lung transplant? .....        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I27. Kidney transplant? .....      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I28. Liver transplant? .....       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I29. Bone marrow transplant? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |
| I30. Other organ transplant? ..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/>                     |

**If yes, specify transplant.**

- |                                      |                          |                          |                          |                      |
|--------------------------------------|--------------------------|--------------------------|--------------------------|----------------------|
| I31. Cataract surgery? .....         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| <b>Males → Go to Question I35.</b>   |                          |                          |                          |                      |
| I32. Removal of one ovary? .....     | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I33. Removal of both ovaries? .....  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I34. Removal of uterus? .....        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| <b>Females → Go to Question I37.</b> |                          |                          |                          |                      |
| I35. Removal of one testis? .....    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I36. Removal of both testes? .....   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |
| I37. Any other surgery? .....        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |

**If yes, specify surgery.**



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. . .

Not sure

Yes, but the condition is no longer present

Yes, and the condition is still present

No

J1. Problems with learning or memory? . . . . .     If yes, age at first occurrence  
years      

**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.

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

J3. Migraine? . . . . .          

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

Not sure

Yes, but the condition is no longer present

Yes, and the condition is still present

No

J4. Other severe headaches? . . . . .     If yes, age at first occurrence  
years      

**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 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.

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)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J13. Paralysis of any kind? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
J14. Have you had a stroke? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**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 past 7 days. 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 distressed or bothered you during the past 7 days 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. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K2. Faintness or dizziness. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K3. Pains in heart or chest. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K4. Thoughts of ending your life . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K5. Suddenly scared for no reason. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K6. Feeling lonely. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K7. Feeling blue. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K8. Feeling no interest in things . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K9. Feeling fearful . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K10. Nausea or upset stomach. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K11. Trouble getting your breath. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K12. Numbness or tingling in parts of your body. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K13. Feeling hopeless about the future. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K14. Feeling weak in parts of your body . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K15. Feeling tense or keyed up. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K16. Spells of terror or panic. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K17. Feeling so restless you couldn't sit still. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K18. Feelings of worthlessness. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

No pain  A lot of pain

Small amount of pain  Very bad, excruciating pain

Medium amount of 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       Severe  
 Mild       Very severe  
 Moderate

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       Quite a bit  
 A little bit       Extremely  
 Moderately

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

- Head       Abdomen  
 Neck       Back  
 Chest       Pelvis  
 Hands/Arms       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

## 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+                       |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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? 

--	--

**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 each of your pregnancies, or each time a woman has become pregnant by you, regardless of the outcome.**

	<u>Pregnancy outcome</u>				Your age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
	Live birth	Stillbirth	Miscarriage	Medical abortion			
Pregnancy 1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 4.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 5.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

**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	Occasionally use	Regularly use
Chewing tobacco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snuff tobacco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pipes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cigars	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>


**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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snuff tobacco	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pipes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cigars	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## 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):

--	--

Glasses a day

Beer  
(12 oz. can):

--	--

Cans a day

Mixed drink  
(1 shot):

--	--

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
- 1 day
- 2 days
- 3 days
- 4 days
- 5 days
- 6 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

**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. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Walking uphill or climbing a few flights of stairs. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bending, lifting, or stooping . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Walking one block . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Eating, dressing, bathing, or using the toilet . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**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 all 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)
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead	
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead	
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> Dead	
	<input type="checkbox"/> Male <input type="checkbox"/> Female		<input type="checkbox"/> Alive <input type="checkbox"/> 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.

		No	Yes	Not sure
<b>Q1a. Have you ever been told by a doctor that you have . . .</b>				
a. Ataxia telangiectasia . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Beckwith-Wiedemann syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bloom's syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Down syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Klinefelter's syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Fanconi's anemia . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Multiple exostoses . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Familial adenomatous polyposis (FAP or Gardner syndrome) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Neurofibromatosis (Type 1) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Nevroid basal cell carcinoma syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Turner's syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Von Hippel-Lindau syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Wiskott-Aldrich syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Xeroderma pigmentosum . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Any other genetic disorder . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*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)**

	<i>What conditions?</i>
<input type="checkbox"/> Mother →	<div style="border: 1px solid black; height: 25px;"></div>
<input type="checkbox"/> Father →	<div style="border: 1px solid black; height: 25px;"></div>
<input type="checkbox"/> Full brother →	<div style="border: 1px solid black; height: 25px;"></div>
<input type="checkbox"/> Full sister →	<div style="border: 1px solid black; height: 25px;"></div>
<input type="checkbox"/> Son →	<div style="border: 1px solid black; height: 25px;"></div>
<input type="checkbox"/> Daughter →	<div style="border: 1px solid black; height: 25px;"></div>

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. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Club foot . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Deafness or impaired hearing at birth . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Blindness or difficulty seeing at birth . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Eyes different colors or missing an iris (the colored part of the eye) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Hydrocephalus (excessive water around or within the brain) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Spina bifida or other neural tube defect . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Unusually small head (microcephaly) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Unequal sized limbs (hemihypertrophy) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Extra fingers, deformed chest, shortened limbs or any other skeletal abnormality . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Hole in the heart or other congenital heart defect . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If other, please specify.*

m. Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines). . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Any kidney, bladder, or genital abnormalities. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Undescended testes. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Any other birth defects . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*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?*

<input type="checkbox"/> Mother	→	
<input type="checkbox"/> Father	→	
<input type="checkbox"/> Full brother	→	
<input type="checkbox"/> Full sister	→	
<input type="checkbox"/> Son	→	
<input type="checkbox"/> Daughter	→	

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

*What types?*

<input type="checkbox"/> Mother	→	
<input type="checkbox"/> Father	→	
<input type="checkbox"/> Full brother	→	
<input type="checkbox"/> Full sister	→	
<input type="checkbox"/> Son	→	
<input type="checkbox"/> 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)**

Learning disabled or special education program? . . . . .

*If yes*, were you in the program because of . . .

- |  | No                       | Yes                      | Not sure                 |
|--|--------------------------|--------------------------|--------------------------|
| a. Missed school. . . . .                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Low scores on tests. . . . .            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Problems learning or concentrating. . . | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Emotional or behavioral problems. . . . | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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 your main job (please give only one):**

**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.) . . . . . | <input type="checkbox"/> | <input type="checkbox"/> |
| Police Department . . . . .           | <input type="checkbox"/> | <input type="checkbox"/> |
| Fire Department. . . . .              | <input type="checkbox"/> | <input type="checkbox"/> |

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

- |                                       |                          |                          |
|---------------------------------------|--------------------------|--------------------------|
| Civilian job . . . . .                | <input type="checkbox"/> | <input type="checkbox"/> |
| Military (Army, Navy, etc.) . . . . . | <input type="checkbox"/> | <input type="checkbox"/> |
| Police Department . . . . .           | <input type="checkbox"/> | <input type="checkbox"/> |
| Fire Department. . . . .              | <input type="checkbox"/> | <input type="checkbox"/> |

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 . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V2. Your ability to have children . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V3. Developing a cancer . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V4. Your ability to get health insurance . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V5. Your ability to get life insurance . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V6. Any other issues . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify.

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