

LTFU

Long-Term Follow-Up Study Sibling Survey

St. Jude Children's Research Hospital
Ann & Robert H. Lurie Children's Hospital of Chicago
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital 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 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 as a brother or sister of an individual treated for childhood cancer, leukemia, tumor or a similar illness. Your participation helps to provide us with valuable information in the fight against these serious illnesses of childhood and adolescence.

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

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

Self Parent Other: _____

If you are completing the survey on the participant's behalf, be aware that all survey questions are about

Today's date:

		/			/				
m	m		d	d		y	y	y	y

Please! Do not mark below this line

Survey #022

6408164368

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

We would like to invite you to take part in the Long-Term Follow-Up Study (LTFU) being conducted by St. Jude Children's Research Hospital. This consent form gives you information about the research 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 take part in this study is entirely up to you.
- If you decide not to be in the study, or to withdraw from the study at any time, it will not affect your relationship with St. Jude or with the original treating institution.
- 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 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 Radiation Physics Center (Houston, TX) 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, compared to their siblings (brothers and sisters). We are interested in studying the risk (chance) of second cancers, long-term side effects of chemotherapy and radiation therapy, and your 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 and Canada, who were treated as children for cancer or a similar illness, will take part in this study. Additionally, about 8,000 siblings will participate as a study comparison group.

What is involved in this study?

You will complete a set of questions about your health. Answering all of the questions will take about 45 minutes. You may leave blank any questions you 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. You may also complete it over the phone with a trained interviewer.

The collected information will be entered into a computer for comparison with people 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, 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 can stop taking part in this study at any time. Whether or not you take part in this study will not affect your relationship with St. Jude or the original treating institution.

Please! Do not mark below this line

What are the risks of the study?

Very rarely, personal information from your records could be given out by accident. To prevent this from happening, electronic data is stored on password protected computers, only study team members work with the data, and study results are reported on the whole group, never identifying one individual in reports. You may become upset by some survey questions and do not have to answer any question that makes you uncomfortable.

What are the benefits of the study?

You may or may not receive a direct benefit from taking part in this study. 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 participation in this study is voluntary. You may choose not to take part in this study.

What about new information?

You will be told of any new information learned during the course of the study, which might cause you to change your mind about staying in the study. You will receive a CCSS Newsletter every six months that contains a study update and other health information that may be helpful to yourself as well as people who were treated for cancer or similar illness. You 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 privacy?

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the federal government. With this Certificate, the researchers cannot be forced to give out your personal information, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other process. The researchers will use the Certificate to block any demands for information that would identify you, except in the cases listed below.

The Certificate cannot be used to resist a demand for information from the United States Government, if that information is used to audit or check federally funded projects or to meet the needs of the U.S. Food and Drug Administration (FDA).

You should know that a Certificate of Confidentiality does not keep you or a member of your family from choosing to give out information about you or your part in this research. If an insurer, employer, or other person gets your written consent to receive research information, then the researchers cannot use the Certificate to keep that information private.

The Certificate of Confidentiality will not keep researchers or hospital staff from making reports required of them. These include reports about suspected child abuse, about diseases that spread from person to person, or about possible threat of harm to yourself or others.

Government agencies oversee research studies involving people. Your research 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 research records to be reviewed by these persons.

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 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: July 19, 2011

The following statement describes your/your child's rights as a research participant:

1. You 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. We may use your information to develop a new product or medical test to be sold. The sponsor, hospital, and researchers may benefit if this happens. There are no plans to pay you if your information is used for this purpose.
4. You will not be charged for being in this research study.
5. If you decide not to be in the study, or to withdraw from the study at any time, it will not affect your relationship with St. Jude.
6. The St. Jude Notice of Privacy Practices tells how your medical information may be used or given to someone outside the hospital. You have the right to read the Notice of Privacy Practices before you sign this form. You can find it at the bottom of every page on the St. Jude Internet website: www.stjude.org.
7. You have the right to see, copy, and ask for changes to your protected health information that will be used or given out. This consent form describes any limits to this right, such as research information that you will not see until the end of the study or that will only be used for research.
8. A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. Law. This Website will not include information that can identify you. At most the Website will include a summary of the results. You can search this Website at any time.
9. Federal agencies such as the Food and Drug Administration (FDA), the Office of Human Research Protections (OHRP) or the National Institutes of Health (NIH), St. Jude Children's Research Hospital Institutional Review Board (IRB), as well as other regulatory agencies, committees, or persons involved in overseeing research studies, may review your research and medical record.
10. Information about you collected as part of this study may be given out as explained in this informed consent form.
11. After your records are given to or used by others, St. Jude Children's Research Hospital cannot promise that information will not be given out again. Also, the information given out may no longer be protected by federal privacy laws.
12. St. Jude uses reasonable safeguards and means to protect the security and confidentiality of e-mail/text messaging, fax information or mail sent to and received from you. However, St. Jude cannot guarantee the security and confidentiality of e-mail or text messaging or fax communications or mail. Despite the best efforts of St. Jude to protect private information, e-mails/text messaging or fax can be electronically taken by other users, changed, forwarded, or used without permission or detection. Possible risks include e-mail/text messaging, fax or mail senders can type the wrong address for an e-mail or mail or dial a wrong phone number. Backup copies of an e-mail/text messaging or fax may exist after the sender or receiver has deleted a copy.
13. Permission to use and give out your child's protected health information will end when your child turns 18 years of age (if applicable). At that time, researchers may get your child's consent if they wish to keep using or giving out your child's protected health information.
14. You may take back permission for your records to be used or given out at any time, for any reason, except the following:
 - When that information has already been given out or used based on your permission
 - When the information is needed to maintain the integrity of the study
15. To take back your permission, please fill out a form called a Revocation of Release of Authorization. You may ask for this form by calling the St. Jude Privacy Officer at 901-595-6141. You must mail the form or hand it to the:

HIPAA Privacy Officer
St. Jude Children's Research Hospital
262 Danny Thomas Place
Memphis, TN 38105
16. If you have more questions about this study, you can call the Principal Investigator of this study, Dr. Leslie Robison, at 901-595-3300.
17. You can get more details 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 at 901-595-4644. If you are outside of the Memphis area, please call toll-free 1-866-583-3472 (1-866-JUDE IRB).

The staff will give you 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

HIPAA Authorization Form

If you sign this form, you are giving St. Jude Children's Research Hospital permission to use or disclose (give out) medical information. It will allow St. Jude to get copies of certain parts of your (your child's) medical record that we may need to review, such as treatment history for your (your child's) childhood illness or records for later illnesses.

LONG-TERM FOLLOW-UP STUDY HIPAA¹ AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION FOR RESEARCH

- Purpose.** As a research participant and at my request, I give Greg Armstrong, M.D., M.S.C.E., and the researcher's staff permission to use and disclose my (my child's) health information for a research project called Long-Term Follow-Up (LTFU) Study.
- Individual Health Information to be Used or Disclosed.** My (My child's) health information that may be used or disclosed for this research may include my (my child's) medical records.
- Who May Disclose My (My Child's) Health Information?** During this study, the researcher and the researcher's staff may get my (my child's) health information from hospitals, clinics, and health care providers who have treated me.
- Who May Receive My (My Child's) Health Information?** The health information disclosed by researchers and information given by me during the research study may be received and used by Greg Armstrong, M.D., M.S.C.E., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Biorepository (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), and the LTFU Statistical Center (Seattle, WA).
- Right to Refuse to Sign this Authorization.** I do not have to sign this form. If I decide not to sign the form, I may not be allowed to take part in this study. However, my decision not to sign this form will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.
- Right to Revoke.** I can change my mind and revoke (take back) this authorization (permission) at any time by sending a written notice of my decision to Dr. Greg Armstrong, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105. If I take back my permission, the researcher may use and disclose only the protected health information already collected for the research study. No further health information about me will be collected by the researcher or disclosed to the researcher for this study.
- Possible Re-disclosure.** After my (my child's) health information is given out under this authorization form, there is a chance that it might be re-disclosed outside this study and no longer covered by this form. However, I understand that the research team and the St. Jude Institutional Review Board (IRB) are very careful to protect my (my child's) privacy and limit the use of information that can identify me (my child). (The IRB is the committee that reviews studies to be sure that the rights and safety of those taking part in the study are protected). In addition, the LTFU study maintains a Certificate of Confidentiality from the National Institute of Health to protect the identity of research subjects.

For those taking part in the research study who are not legal adults, this authorization form will expire when they become legal adults (unless the person taking part in the study has appointed a legal guardian to provided authorization). A new form will be required when the child becomes a legal adult. For a legal adult taking part in this study, this authorization (permission) expires at the end of the study.

I am the research participant, or I am legally authorized to act on behalf of the person taking part in the study.

I have read this information and have received a copy of the form.



Printed name of research participant

Date of birth

Signature of research participant or legal guardian

Date



Printed name of legal guardian

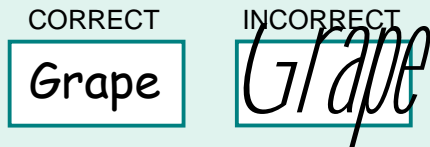
Describe how the person signing has authority to act on behalf of the research participant

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

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	Yes	Not sure	↓ 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. Concerning your current residence, do you:

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

Specify

A9. 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 **May 2012 and May 2014**.

B1. Between May 2012 and May 2014, 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 B6.
- 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 7 - 10 times
- 1 - 2 times 11 - 20 times
- 3 - 4 times More than 20 times
- 5 - 6 times

B4. 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

B5. During this 2 year period, how many times were you admitted to any hospital?

--	--

B6. 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

B7. Please indicate all medicines/drugs you took *regularly* during the two-year period between **May 2012 and May 2014.**

- 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).

1. 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

2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle-----

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

3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate-----

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

4. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)-----

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

5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others-----

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

	Not sure			If yes, age at first use		If yes, are you currently taking any of these?	
	No	Yes	Not sure	years		No	Yes
1. BIRTH CONTROL PILLS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ESTROGENS OR PROGESTERONES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. TESTOSTERONES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. PILLS OR INSULIN FOR DIABETES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B7. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between **May 2012 and May 2014.**

- 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?

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

No Yes

years

No Yes

7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT-----

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

8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others-----

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

9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil-----

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

10. OTHER PRESCRIBED DRUGS-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name **and** specify the reason the drug was prescribed.

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"/>
<i>If yes, do you have any sight?</i> <input type="checkbox"/> No <input type="checkbox"/> Yes					
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, 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"/>
---	--------------------------	--------------------------	--------------------------	--------------------------	----------------------

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
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"/> years
F2. A myocardial infarction (heart attack)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years
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"/> years
F4. Coronary heart disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/> years

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"/>
<p>If yes, do you currently take medication for this? <input type="checkbox"/> No <input type="checkbox"/> Yes</p>					
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"/>
If yes, what type(s)? (Mark all that apply)					
<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"/>
If yes, describe.					
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"/>
If yes, specify (example: left hand, right foot).				
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"/>
If yes, specify.				
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"/>
If yes, specify.				
I6. Other bone surgery?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
If yes, specify.				
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
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
years |
|----------------------------------|--------------------------|--------------------------|--------------------------|--|
| I23. Any lung surgery? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> |

If yes, specify.

- | | | | | |
|---|--------------------------|--------------------------|--------------------------|----------------------|
| 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"/> |
|----------------------------------|--------------------------|--------------------------|--------------------------|----------------------|

Males → Go to Question I35.

- | | | | | |
|---|--------------------------|--------------------------|--------------------------|----------------------|
| 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"/> |

Females → Go to Question I37.

- | | | | | |
|--|--------------------------|--------------------------|--------------------------|----------------------|
| 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. . .

	No		Not sure		If yes, age at first occurrence years
Yes, but the condition is no longer present Yes, and the condition is still present					
J1. Problems with learning or memory?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>

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? . . .	<input type="checkbox"/>		Not sure		If yes, age at first occurrence years
If yes, describe this problem and list medications.					
If yes, are you currently taking medication for this? <input type="checkbox"/> No <input type="checkbox"/> Yes					
J3. Migraine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>

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

	No		Not sure		If yes, age at first occurrence years
Yes, but the condition is no longer present Yes, and the condition is still present					
J4. Other severe headaches?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>

If yes, list medications if required to control.

J5. Problems with balance, equilibrium, or ability to reach for or manipulate objects? . . .	<input type="checkbox"/>		Not sure		If yes, age at first occurrence years
If yes and still present, please rate the severity of these problems:					
<input type="checkbox"/> <u>Mild</u> ; does not affect walking or my daily routine. <input type="checkbox"/> <u>Moderate</u> ; it is bothersome and affects my walking but I am able to do my daily routine. <input type="checkbox"/> <u>Severe</u> ; this problem significantly affects my walking and my daily routine. <input type="checkbox"/> <u>Disabling</u> ; I require a wheelchair or cannot walk because of this problem.					
J6. Tremors or problems with movements?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>

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.

J7. Problems chewing or swallowing solids or liquids? . . .	<input type="checkbox"/>		Not sure		If yes, age at first occurrence years
If yes, describe this problem and list medications.					
J8. Decreased sense of touch or feeling in hands, fingers, arms or legs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>
J9. Prolonged pain in arms, legs or back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>
J10. Abnormal sensation in arms, legs or back?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>
J11. Weakness or inability to move arm(s)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input style="width: 30px; height: 20px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>

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. . .

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	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?	<input type="checkbox"/> No <input type="checkbox"/> Yes				
b. Did it affect:					
Speech.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Only one side of the body . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Both sides of the body . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
c. Did you lose consciousness?	<input type="checkbox"/> No <input type="checkbox"/> Yes				
d. Did you have weakness or inability to move arm(s)? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
e. Did you have weakness or inability to move leg(s)? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
f. Did you have paralysis of any kind?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

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

None **→ Go to Question L1, next page.**

Very mild

Mild

Moderate

Severe

Very severe

K20. 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

K21. 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

The following questions (L1-L9) relate to whether you have ever been diagnosed with cancer, leukemia, tumor or other similar illness.

L1. Have you ever been diagnosed with cancer, leukemia, tumor, or similar illness?

- 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:

Date of Diagnosis:

Month		Year			

L5. Have you had any additional cancers, leukemias, tumors, or similar illnesses after this diagnosis? (Include any relapse or recurrence of your original diagnosis.)

- No **→ Go to Question M1.**
 Yes

L6. Please write the name of this disease.

L7. Did you have treatment for this disease?

- No **→ Skip L7a and go to Question L8.**
 Yes

L7a. What treatments did you receive? (Mark all that apply)

- Chemotherapy Radiation therapy Surgery

L8. Where was this diagnosed?

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

L9. Was this a:

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

Date of Recurrence or New 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.)

	Not limited at all	Limited for 3 months or less	Limited for more than 3 months
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 P1a.

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 <u>first</u> mammogram:	
Age at <u>last</u> mammogram:	

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.

P1a. Have you ever been told by a doctor that you have...

	Not sure		
	No	Yes	
a. Ataxia telangiectasia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Beckwith-Wiedemann syndrome	<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"/>
d. Bloom's syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Down syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Klinefelter's syndrome.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Fanconi's anemia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Multiple exostoses	<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"/>
j. Neurofibromatosis (Type 1).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Nevoid basal cell carcinoma syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Turner's syndrome.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Von Hippel-Lindau syndrome.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Wiskott-Aldrich syndrome.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Xeroderma pigmentosum.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Any other genetic disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If yes, describe this disorder.

P1b. If you have children (blood relatives only), have they ever had any of the above conditions? (Mark all that apply)

What conditions?

Son →

Daughter →

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.

P2. Have you ever had genetic counseling for cancer risk?

- No
 Yes

P3a. 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.

P3b. If you have children (blood relatives only), have they ever had any of the conditions in Question P3a? (Mark all that apply)

What conditions?

- Son →
- Daughter →

P4. If you have children (blood relatives only), have they ever had cancer? (Mark all that apply)

What types?

- Son →
- Daughter →

SCHOOL HISTORY

Q1. 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

Q2. 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

Q3. In elementary, junior, or high school were you ever in any of the following programs? (Mark all that apply)

	No	Yes	Not sure
Learning disabled or special education program?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes , were you in the program because of. . .			
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? .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homebound education for at least one school year?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q4. If you were in a learning disabled or special education program, what grades were you in at that time? (Mark all that apply)

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

EMPLOYMENT HISTORY

R1. Have you ever had a job?

- No → Go to Question R4.
- Yes ↴

R2. 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 R4.
- 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.

R3. 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):

R3a. Main job title:

R3b. Please briefly describe your primary job tasks:

R4. 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"/>

R5. 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"/>

INCOME

S1. Over the last year, what was the total income of the household you live in?

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

S2. During the past year, how many people in this household were supported on this income?

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

S3. Over the last year, what was your personal income?

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

INSURANCE

T1. Have you ever had difficulty obtaining health insurance because of your health history?

- No
- Yes

T2. Do you currently have health insurance coverage?

- Canadian resident → Go to Question T4.
- No → Go to Question T4.
- Yes

T3. 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.

T3a. Does this health insurance plan have any exclusions or restrictions because of your health history?

- Don't know
- No
- Yes

Specify.

T3b. Is there an extra premium charge on your health insurance policy because of your health history?

- Don't know
- No
- Yes

T4. Have you ever had difficulty obtaining life insurance because of your health history?

- No
- Yes
- Never tried to obtain life insurance

T5. Do you currently have life insurance coverage?

- No
- Yes

OTHER ISSUES

Please rate how concerned you are about the following:

	Not at all concerned				
	Not very concerned				
	Concerned				
	Somewhat concerned				
	Very concerned				
U1. Your future health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
U2. Your ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
U3. Developing a cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
U4. Your ability to get health insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
U5. Your ability to get life insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
U6. Any other issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please specify.

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



<i>Your Email Address</i>

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!