Last modified:
05/21/2010 10:29:12 AM

LTFU

Long-Term Follow-Up Study
Sibling Survey

St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital of Columbus
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
Dana-Farber Cancer Institute
Loma Linda University
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller 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
The Denver Children's Hospital
Toronto Hospital for Sick Children
UAB/The Children's Hospital of Alabama
University of California at San Francisco
University of Michigan - Mott Children's Hospital
University of Minnesota
U.T.M.D. Anderson Cancer Center

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

and

UNIVERSITY OF MINNESOTA

Thank you for participating in the Long-Term Follow-Up Study. Your participation continues to provide us with valuable information in the fight against childhood cancer and similar illnesses.

It has been about four years since we sent you our last general survey and we would like to update your information. Please fill out the following form that will bring us up-to-date on your health in the past two years. The length of time to complete varies between individuals, but generally requires 30-60 minutes.

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: _____

Today's date: ☐☐ / ☐☐ / ☐☐☐☐

Please! Do not mark below this line

Edit ☐ Survey #009 Code ☐

0052255043

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. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:

CORRECT

Grape

INCORRECT

MARKING EXAMPLES

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

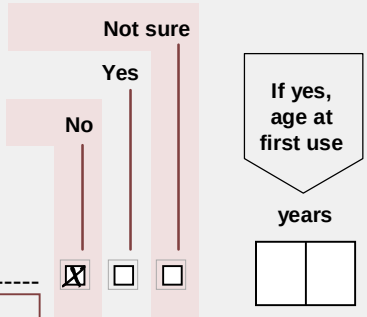
Example 1

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

☐ No ☒ Yes

Example 2

2. Have you ever taken. . .



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?

0	4		1	9	9	5

Month (mm) Year (yyyy)

Please! Do not mark below this line

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In the past we have asked you questions similar to those below. We would like to update this information.

A1. What is your current height without shoes?

Feet Inches

A2. What is your current weight without shoes?

Pounds

A3. What is the highest grade or level of schooling you have now 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

If Other, please describe.

A4. What is your current employment status? Include unpaid work in the family business or farm. ***(Mark all that apply)***

- ☐ 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

If Other, please describe.

If you are <u>not</u> currently working full or part time. . . → ***Go to Question A6.***

A5. 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:

A5a. Main job title:

A5b. Please briefly describe the primary tasks in your job:

Please! Do not mark below this line

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A6. Over the last year, what was the total income of the household you live in?

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

A7. During the past year, how many people in this household were supported on this income?

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

A8. Over the last year, what was your personal income?

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

MEDICAL CARE

The next questions are about health care received during the 2 year period between November 2007 and November 2009.

B1. During this two year period, which of the following health care providers (excluding dentists) did you see or talk to for medical care? This includes routine and sick care. *(Mark all that apply)*

- ☐ None → *Go to Question B5, next page.*
- ☐ Physician (including Osteopath)
- ☐ Nurse Practitioner/Physician's Assistant
- ☐ Nurse
- ☐ Chiropractor
- ☐ Physical therapist
- ☐ Other

If Other, please describe.

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

If Other, please describe.

Please! Do not mark below this line

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

- ☐ None
- ☐ 1-2 times
- ☐ 3-4 times
- ☐ 5-6 times
- ☐ 7-10 times
- ☐ 11-20 times
- ☐ More than 20 times

B4. Did you discuss any of the following issues with your physician or primary health care provider during any of these visits?

	No	Yes
a. Heart disease	☐	☐
b. Osteoporosis (weak or brittle bones)	☐	☐
c. Risk of developing cancer (breast, skin, other)	☐	☐
d. Hepatitis C	☐	☐
e. Dental problems	☐	☐
f. Fertility issues	☐	☐
g. Mental health	☐	☐
h. Other issues related to cancer or other serious illness during childhood	☐	☐

If Other issues, please describe.

B5. Do you currently have health insurance coverage?

- ☐ Canadian resident
- ☐ No
- ☐ Yes

MEDICAL SCREENING TESTS

The following questions are about medical screening tests you may have received.

When was the last time you had . . .

C1. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or MUGA scan?

- ☐ 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

C2. A test to measure your bone strength or bone mineral density (such as a DEXA or quantitative CT scan)?

- ☐ 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

C3. A blood stool test is a test that may use a special kit at home to determine whether the stool contains blood.

When was the last time that you had a blood stool test using a home kit?

- ☐ 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

C4. Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems.

When was the last time you had either of these exams?

- ☐ 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 C8, page 7.*

FEMALES

When was the last time you had . . .

C5. A mammogram?

- ☐ 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

C6. A breast MRI?

- ☐ 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

C7. 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

Continue on next page.

C8. Please indicate all medicines/drugs you took *regularly* during the two-year period between November 2007 and November 2009.

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

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

Please! Do not mark below this line

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C8. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between November 2007 and November 2009.

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

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

Please! Do not mark below this line

Medical Conditions

The next series of questions relate to medical conditions that you have ever had. You may have previously told us about some of these conditions. We are asking again to make sure our records are current and to capture occurrences of new medical conditions.

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. If you answer "yes", please give your 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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
D1. Hearing loss requiring a hearing aid?	☐	☐	☐	☐	
D2. Deafness in both ears not completely corrected by hearing aid?	☐	☐	☐	☐	
D3. Deafness in only one ear not completely corrected by hearing aid?	☐	☐	☐	☐	
D4. Tinnitus or ringing in the ears?	☐	☐	☐	☐	
D5. Persistent dizziness or vertigo?	☐	☐	☐	☐	
D6. Hearing loss, not requiring a hearing aid?	☐	☐	☐	☐	
D7. Any other hearing problems?	☐	☐	☐	☐	

If yes, describe this problem.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
D8. 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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
D9. Legally blind in both eyes?	☐	☐	☐	☐	

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

D10. Cataracts?	☐	☐	☐	☐	
D11. Glaucoma (excess pressure in the eyeball)?	☐	☐	☐	☐	
D12. Problems with double vision?	☐	☐	☐	☐	
D13. A detached retina or any other condition of the retina?	☐	☐	☐	☐	

If yes, describe this problem.

D14. Crossed or turned eyes (strabismus)?	☐	☐	☐	☐	
D15. Lazy eye (amblyopia)?	☐	☐	☐	☐	
D16. Any other trouble seeing with one or both eyes even when wearing glasses?	☐	☐	☐	☐	
D17. Very dry eyes requiring eye drops or ointment?	☐	☐	☐	☐	
D18. Any other eye problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

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

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
D19. Stammering or stuttering? . .	☐	☐	☐	☐	
D20. Any other speech defects? . .	☐	☐	☐	☐	

If yes, describe this defect.

D21. Abnormal sense of taste?. . .	☐	☐	☐	☐	
D22. Loss of taste or smell lasting for 3 months or more?	☐	☐	☐	☐	

URINARY SYSTEM

E1. Kidney stones?.	☐	☐	☐	☐	
E2. REPEATED (more than 3 in any 12 month period) kidney or bladder infections?	☐	☐	☐	☐	
E3. Dialysis?.	☐	☐	☐	☐	
E4. Blood in your urine?.	☐	☐	☐	☐	
E5. Urinary incontinence?.	☐	☐	☐	☐	
E6. Any other kind of kidney, bladder or urinary tract disorder?	☐	☐	☐	☐	

If yes, describe this disorder.

HORMONAL SYSTEMS

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
F1. An overactive thyroid gland (hyperthyroid)?	☐	☐	☐	☐	
F2. An underactive thyroid gland (hypothyroid)?.	☐	☐	☐	☐	
F3. Thyroid nodules?	☐	☐	☐	☐	
F4. Swollen or enlarged thyroid gland?	☐	☐	☐	☐	
F5. Diabetes that can be controlled with diet?.	☐	☐	☐	☐	
F6. Diabetes controlled with pills or tablets?	☐	☐	☐	☐	
F7. Diabetes controlled with insulin shots?	☐	☐	☐	☐	
F8. Deficiency of growth hormone?.	☐	☐	☐	☐	
F9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?.	☐	☐	☐	☐	
F10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?.	☐	☐	☐	☐	
F11. Have you ever broken a bone?.	☐	☐	☐	☐	

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

F12. Any other hormonal problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

Males → Go to Question F17.

F13. **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 F15.

F14. **FEMALES** - At what age did you last have a menstrual period naturally, without needing hormones or medication?

☐☐ **years and** ☐☐ **months old**

F15. **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 G1.
If you selected e, f, or g → Go to Question F16.

F16. **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.

Females → Go to Question G1.

F17. **MALES -**

LTFU Questionnaire on Men's Health

We are conducting an additional study funded by the Lance Armstrong Foundation to better understand fertility and sexual function in males. Participation would require 30-40 minutes. Because some of the questions are of a personal nature we would send you a separate questionnaire. Would you consider participating?

☐ Yes ☐ No ☐ Not Sure

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)
G1. Congestive heart failure or cardiomyopathy (weak heart muscle)?	☐	☐	☐	☐	☐☐
G2. A myocardial infarction (heart attack)?	☐	☐	☐	☐	☐☐
G3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor?	☐	☐	☐	☐	☐☐
G4. Coronary heart disease?	☐	☐	☐	☐	☐☐

If yes, describe this problem.

G5. Hypertension (high blood pressure) requiring medication?	☐	☐	☐	☐	☐☐

If yes, do you currently take hypertension medication?

☐ No ☐ Yes

Please! Do not mark below this line

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

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

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
G6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)?	☐	☐	☐	☐	
G7. Pericarditis or fluid around the heart?	☐	☐	☐	☐	
G8. Pericardial constriction (scarring or tightness of the sac around the heart)?	☐	☐	☐	☐	
G9. Stiff or leaking heart valves?	☐	☐	☐	☐	
G10. Blood clot in head, lung, arm, leg, or pelvis?	☐	☐	☐	☐	
G11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat?	☐	☐	☐	☐	
G12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	

If yes, do you currently take medication for this?
☐ No ☐ Yes

G13. Any other heart or circulatory problems?	☐	☐	☐	☐	

If yes, describe this problem.

G14. 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 (years)
H1. Asthma?	☐	☐	☐	☐	
H2. Chronic cough or shortness of breath for more than one month?	☐	☐	☐	☐	
H3. Have you had a need for extra oxygen?	☐	☐	☐	☐	
H4. Pneumonia, 3 or more times in the past 2 years?	☐	☐	☐	☐	
H5. Emphysema?	☐	☐	☐	☐	
H6. Lung fibrosis or "scarring" of the lung?	☐	☐	☐	☐	
H7. Problems with breathing while at rest that lasted for more than 3 months?	☐	☐	☐	☐	
H8. Any other breathing or lung problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

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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)
I1. Hepatitis?	☐	☐	☐	☐	

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

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

I2. Cirrhosis of the liver?	☐	☐	☐	☐	
I3. Any other liver trouble?	☐	☐	☐	☐	

If yes, describe.

I4. Intestinal (colon) polyps?	☐	☐	☐	☐	
I5. Fatty liver?	☐	☐	☐	☐	
I6. Esophageal strictures (narrowing of the esophagus)?	☐	☐	☐	☐	
I7. Rectal or anal fistula?	☐	☐	☐	☐	
I8. Rectal or anal stricture (narrowing or scarring)?	☐	☐	☐	☐	
I9. Any other stomach or digestive trouble?	☐	☐	☐	☐	

SURGICAL PROCEDURES

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

	No	Yes	Not sure	If yes, age at first occurrence (years)
J1. Amputation of an arm, leg, hand, foot?	☐	☐	☐	

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

J2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)?	☐	☐	☐	
J3. Other surgery of spinal cord or spine?	☐	☐	☐	

J4. Leg lengthening or shortening procedures?	☐	☐	☐	
J5. Joint replacement?	☐	☐	☐	

If yes, specify.

J6. Other bone surgery?	☐	☐	☐	

If yes, specify.

J7. Coronary artery bypass surgery?	☐	☐	☐	
J8. Pericardiectomy (stripping of the sac around the heart)?	☐	☐	☐	

Please! Do not mark below this line

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

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

	No	Yes	Not sure	If yes, age at first occurrence (years)
J9. Heart catheterization ("heart cath")?	☐	☐	☐	
J10. Angioplasty (enlarging a heart vessel using a balloon)?	☐	☐	☐	
J11. Surgery for heart valve replacement?	☐	☐	☐	
J12. Surgery for pacemaker?	☐	☐	☐	
J13. Other heart surgery?	☐	☐	☐	

If yes, specify.

	No	Yes	Not sure	If yes, age at first occurrence (years)
J14. Surgery for intestinal obstruction (blocked intestines)?	☐	☐	☐	
J15. Colostomy or ileostomy (stool going into a bag)?	☐	☐	☐	
J16. Biopsy or removal of lump in thyroid gland?	☐	☐	☐	
J17. Removal of part or all of the thyroid gland?	☐	☐	☐	
J18. Removal of the spleen?	☐	☐	☐	
J19. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid?	☐	☐	☐	
J20. Breast biopsy?	☐	☐	☐	
J21. Breast-conserving or breast-sparing surgery (lumpectomy)?	☐	☐	☐	
J22. Mastectomy or removal of a breast?	☐	☐	☐	

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

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

	No	Yes	Not sure	If yes, age at first occurrence (years)
J23. Any lung surgery?	☐	☐	☐	

If yes, specify.

J24. Periodontal (gum) surgery?	☐	☐	☐	
J25. Heart transplant?	☐	☐	☐	
J26. Lung transplant?	☐	☐	☐	
J27. Kidney transplant?	☐	☐	☐	
J28. Liver transplant?	☐	☐	☐	
J29. Bone marrow transplant?	☐	☐	☐	
J30. Other organ transplant?	☐	☐	☐	

If yes, specify transplant.

J31. Cataract surgery?	☐	☐	☐	

Males → Go to Question J35.

J32. Removal of one ovary?	☐	☐	☐	
J33. Removal of both ovaries?	☐	☐	☐	
J34. Removal of uterus?	☐	☐	☐	

Females → Go to Question J37.

J35. Removal of one testis?	☐	☐	☐	
J36. Removal of both testes?	☐	☐	☐	
J37. Any other surgery?	☐	☐	☐	

If yes, specify surgery.

Please! Do not mark below this line

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

BRAIN AND NERVOUS SYSTEM

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
K1. Problems with learning or memory?	☐	☐	☐	☐	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.

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
K2. Epilepsy, repeated seizures, convulsions, or blackouts? . . .	☐	☐	☐	☐	years ☐☐

If yes, describe this problem and list medications.

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

K3. Migraine?	☐	☐	☐	☐	☐☐
K4. Other severe headaches? . . .	☐	☐	☐	☐	☐☐

If yes, list medications if required to control.

Continue on next page.

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)
K5. Problems with balance, equilibrium, or ability to reach for or manipulate objects?	☐	☐	☐	☐	

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

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

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
K6. Tremors or problems with movements?	☐	☐	☐	☐	
K7. Problems chewing or swallowing solids or liquids?	☐	☐	☐	☐	
K8. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
K9. Prolonged pain in arms, legs or back?	☐	☐	☐	☐	
K10. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
K11. Weakness or inability to move arm(s)?	☐	☐	☐	☐	
K12. Weakness or inability to move leg(s)?	☐	☐	☐	☐	
K13. Paralysis of any kind?	☐	☐	☐	☐	

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)
K14. Have you had a stroke?	☐	☐	☐	☐	

If yes, as a result of the stroke . . .

a. Did the symptoms last more than 24 hours?
☐ No ☐ Yes

b. Did it affect:

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure
Speech	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐

c. Did you lose consciousness?
☐ No ☐ Yes

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	
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.

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	
K15. Any other brain or nervous system problems?	☐	☐	☐	☐	

If yes, describe this problem.

Please! Do not mark below this line

Questions L1 to L18 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
L1. Nervousness or shaking inside	☐	☐	☐	☐	☐
L2. Faintness or dizziness	☐	☐	☐	☐	☐
L3. Pains in heart or chest	☐	☐	☐	☐	☐
L4. Thoughts of ending your life	☐	☐	☐	☐	☐
L5. Suddenly scared for no reason	☐	☐	☐	☐	☐
L6. Feeling lonely	☐	☐	☐	☐	☐
L7. Feeling blue	☐	☐	☐	☐	☐
L8. Feeling no interest in things	☐	☐	☐	☐	☐
L9. Feeling fearful	☐	☐	☐	☐	☐
L10. Nausea or upset stomach	☐	☐	☐	☐	☐
L11. Trouble getting your breath	☐	☐	☐	☐	☐
L12. Numbness or tingling in parts of your body	☐	☐	☐	☐	☐
L13. Feeling hopeless about the future	☐	☐	☐	☐	☐
L14. Feeling weak in parts of your body	☐	☐	☐	☐	☐
L15. Feeling tense or keyed up	☐	☐	☐	☐	☐
L16. Spells of terror or panic	☐	☐	☐	☐	☐
L17. Feeling so restless you couldn't sit still	☐	☐	☐	☐	☐
L18. Feelings of worthlessness	☐	☐	☐	☐	☐

L19. In general, would you say your health is:

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

L20. How much bodily pain have you had during the past 4 weeks?

- ☐ None → *Go to Question M1, next page.*
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

L21. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

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

L22. For pain that you have had during the past 4 weeks, where has this pain been located? ***(Check all that apply)***

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

Specify

Please! Do not mark below this line

MARITAL STATUS

M1. What is your current living arrangement? ***(Mark all that apply)***

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

Specify

M2. Which of the following best describes your <u>current</u> marital status?

- ☐ Single, never married or never lived with partner as married → ***Go to Question N1.***
- ☐ Married
- ☐ Living with partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

M3. How many times have you been married or lived as married?

1	2	3	4	5	6	7	8	9+
☐	☐	☐	☐	☐	☐	☐	☐	☐

HEALTH HABITS

<u>Alcohol</u>

N1. In your entire life, have you ever had at least 2 drinks of any kind of alcoholic beverage?

- ☐ No → ***Go to Question N7, next page.***
- ☐ Yes

N2. How old were you when you first started drinking alcohol?

☐☐

N3. During the last 12 months, <u>how many</u> alcoholic drinks did you have on a typical day when you drank alcohol? ***(If less than one per day, enter 0.)***

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

N4. 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

Please! Do not mark below this line

N5. 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

N6. 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
- ☐ two days a week
- ☐ one day a week
- ☐ 2 to 3 days a month
- ☐ one day a month
- ☐ 3 to 11 days in the past year
- ☐ 1 or 2 days in the past year
- ☐ Never in the past year

Smoking

N7. Have you smoked at least 100 cigarettes in the previous two years?

- ☐ No → *Go to Question N13.*
- ☐ Yes

N8. If you started smoking since you last provided us this information on %N8date%, how old were you when you started smoking?

☐☐

N9. Do you smoke cigarettes now?

- ☐ No
- ☐ Yes

N10. On average, how many cigarettes a day do/did you smoke?

☐☐

N11. How many years, in total, have you smoked?

☐☐

N12. 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?

☐☐

N13. In the past year, have you ever used any of these tobacco products? ***(Mark all that apply)***

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

N14. For any of those that you have used or are currently using, how long have you used it?

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

Please! Do not mark below this line

Physical Activity

The following questions are about exercise, recreation, or physical activities other than your regular job duties.

N15. 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

We are interested in two types of physical activity: vigorous and moderate.
- **Vigorous activities cause large increases in breathing or heart rate.**
- **Moderate activities cause small increases in breathing or heart rate.**

N16. Now thinking about the vigorous physical activities you do in a usual week, do you do vigorous activities for at least 10 minutes at a time, such as running, aerobics, wheelchair basketball, heavy yard work, or anything else that causes large increases in breathing or heart rate?

☐ No → *Go to Question N19.*

☐ Yes

N17. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

☐☐ Days per week

N18. On days when you do vigorous activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

N19. Now, thinking about the moderate physical activities you do in a usual week, do you do moderate activities for at least 10 minutes at a time, such as brisk walking, bicycling, gardening, manual operation of a wheelchair, or anything else that causes small increases in breathing or heart rate?

☐ No → *Go to Question N22.*

☐ Yes

N20. How many days per week do you do these moderate activities for at least 10 minutes at a time?

☐☐ Days per week

N21. On days when you do moderate activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

N22. 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

N23. 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

N24. Does any impairment or health problem keep you from holding a job or attending school?

☐ No

☐ Yes

N25. Do you currently have a driver's license?

☐ No

☐ Yes

Please! Do not mark below this line

N26. 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.	☐	☐	☐
b. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling	☐	☐	☐
c. Walking uphill or climbing a few flights of stairs.	☐	☐	☐
d. Bending, lifting, or stooping	☐	☐	☐
e. Walking one block	☐	☐	☐
f. Eating, dressing, bathing, or using the toilet	☐	☐	☐

OTHER ISSUES

Please rate how concerned you are about the following:	Not at all concerned	Not very concerned	Concerned	Somewhat concerned	Very concerned
O1. Your future health	☐	☐	☐	☐	☐
O2. Your ability to have children	☐	☐	☐	☐	☐
O3. Developing a cancer	☐	☐	☐	☐	☐
O4. Your ability to get health insurance.	☐	☐	☐	☐	☐
O5. Your ability to get life insurance . . .	☐	☐	☐	☐	☐
O6. Any other issues	☐	☐	☐	☐	☐

Please specify.

CANCER, LEUKEMIA, OR TUMOR

P1. Have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse) since you last provided us information in %LastMo%, %LastYr%? (Please include skin cancers.)

☐ No → *Go to next page.*

☐ Yes

What was the name of this disease?

If this was a skin cancer, where was it located on your body? (Example: right upper arm, left ear)

Where was this diagnosed?

Doctor's name

Hospital or clinic

Address

City, State, Zipcode

Was this a:

☐ New cancer, leukemia, tumor, or similar illness

☐ Recurrence of a previous diagnosis

☐ Don't know

Date of New Diagnosis or Recurrence:

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

Please use a separate sheet of paper for additional cancers

Please! Do not mark below this line

FAMILY HISTORY INFORMATION

Conditions or illnesses occurring in family members may be important clues in determining our genetic make-up. The following section of the questionnaire deals with cancer, conditions present at birth, and hereditary conditions that may be present in your children. Please use the list below to complete the following section.

Cancer

Any diagnosis of cancer or malignant tumor, such as:

Leukemia
Retinoblastoma
Brain tumor
Hodgkins disease
Sarcoma
Germ cell tumor
Cancer - any other type, or location unknown
Skin cancer - Please note if melanoma or non-melanoma
Wilms tumor
Lymphoma
Teratoma
Seminoma
Neuroblastoma
Carcinoma

Conditions Present at Birth

Any abnormality present at birth, such as:

Blindness or difficulty seeing
Crossed eyes (strabismus)
Eyes different colors
Hare lip (cleft lip)
Hole in roof of mouth (cleft palate)
Absent, fused or extra fingers or toes
Hip displacement
Diverted urinary stream (hypospadias)
Undescended testicle (cryptorchism)
Deafness or impaired hearing
Shortened limbs
Club foot
Hole in the heart
Other congenital heart defect
Down Syndrome Trisomy 21
Open spine (spina bifida)
Exposed brain (anencephaly)
Large or multiple birth marks
Water on the brain (hydrocephalus)
Macrocephaly (enlarged head)
Microcephaly (small head)
Hemihypertrophy (enlargement of one arm or leg)
Deformed chest
Other skeletal abnormality

Hereditary Conditions

Some of the more common conditions known to be hereditary:

Achondroplasia
Acrocephalosyndactyly
Aniridia (missing an iris)
Apert's syndrome
Ataxia-telangiectasia
Beckwith-Wiedemann syndrome
Bilateral acoustic neurofibromatosis (type 2)
Bloom's syndrome
Congenital megacolon (Hirschsprung's disease)
Cystic fibrosis
Fanconi's anemia
Klinefelter's syndrome
Marfan's syndrome
Multiple exostoses
Multiple polyposis
Myotonic dystrophy
Neurofibromatosis (type 1)
Nevoid basal cell carcinoma syndrome
Osteogenesis imperfecta
Polycystic disease of the kidney
Polyposis coli (Gardner syndrome)
Tuberous sclerosis
Turner's syndrome
Von Hippel-Lindau syndrome
Von Recklinghausen's disease
Wiskott-Aldrich syndrome
Xeroderma pigmentosum

PREGNANCY AND OFFSPRING

Q1. Have you, or your partner, had any new pregnancies since you last provided us with this information on %Alldates%?

☐ No → *Go to Question R1 on page 25.*

☐ Yes

Q2. Are you, or your partner, currently pregnant?

☐ No

☐ Yes

Q3. Please write down the names of each of your children who have been born since %Alldates%. Indicate whether each child has a history of cancer, a birth defect, and/or any hereditary conditions (refer to the list of conditions on the previous page). Please list twin births or multiple births as separate children.
Use a separate piece of paper if you need to record more pregnancies.

Full Name (First, Middle, Last)	Sex	Date of Birth (Mo/Day/Yr)	Status	Date of Death (Mo/Day/Yr)	Medical history of cancer, birth defect, hereditary condition. Provide specific type.	Age of onset (yrs)
	☐ Male ☐ Female		☐ Alive ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			

Q4. This question concerns the birth (biological) parents of your children listed above. Please list the other parent or parents of your children. ***Use a separate sheet of paper if you need to record additional parents.***

Full Name of other parent (First, Middle, Last)	Date of Birth (Mo/Day/Yr)	Status	Date of Death (Mo/Day/Yr)	Medical history of cancer, birth defect, hereditary condition Provide specific type.	Age of onset (yrs)
		☐ Alive ☐ Dead			
Please list the names of the biological children of this parent.					

Please! Do not mark below this line

Q5. Since %Alldates%, 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.

Pregnancy outcome

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

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

Continue on next page.

OTHER TREATMENT

We are interested in whether you have had any radiation or chemotherapy for cancer or similar illness. Radiation is a treatment you would have received in a radiation therapy department and does not include CAT scans, MRI's, or diagnostic x-rays.

R1. Have you ever received any radiation treatment?

☐ No → *Go to Question R2.*

☐ Yes

☐ Not sure

If yes, please indicate the date of any (additional) radiation treatment you received for a recurrence or a new cancer.

Date of Treatment

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

Please indicate the reason for radiation.

Where was the radiation performed?

Hospital or clinic
Address
City, State, Zipcode
Doctor's name

R2. Have you ever received any chemotherapy treatment?

☐ No → *Go to next page.*

☐ Yes

☐ Not sure

If yes, please indicate the date of any (additional) chemotherapy treatment you received for a recurrence or a new cancer.

Date of Treatment

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

Please indicate the reason for chemotherapy.

Where was the chemotherapy performed?

Hospital or clinic
Address
City, State, Zipcode
Doctor's name

Continue on next page.

Please! Do not mark below this line

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

LONG-TERM FOLLOW-UP STUDY

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

1. Purpose. As a research participant, 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: _____
Other Providers: _____
Health Plan: _____,
and from hospitals, clinics, health care providers and health plans that provide my health care during the study.

4. Parties Who May Receive or Use My Individual Health Information. The individual health information disclosed by parties listed in item 3 and information disclosed by me during the course of the research may be received and used by Leslie L. Robison, Ph.D., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Molecular Center (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), and the LTFU Statistical Center (Seattle, WA).

5. Right to Refuse to Sign this Authorization. I do not have to sign this Authorization. If I decide not to sign the Authorization, I may not be allowed to participate in this study. However, my decision not to sign this authorization will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.

6. Right to Revoke. I can change my mind and withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, 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 will 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.

This authorization does not have an expiration date.

I am the research participant or personal representative authorized to act on behalf of the participant.

I have read this information, and I will receive a copy of this authorization form after it is signed.

Sign Here

_____ Printed name of research participant

_____ Date of birth

Fill in Date

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

_____ Today's Date

_____ Printed name of research participant's personal representative

_____ Description of personal representative's authority to act on behalf of the research participant

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

Please! Do not mark below this line

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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

If this information is not correct, please give us your correct address or location:

Address	
City	State
Zip Code	Phone Number

Please provide the name and address of someone who could give us your new address should you move. We will contact this person only if we are unable to reach you at your home address.

Name	
Address	Relationship to you
City	State
Zip Code	Phone Number

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

☐ No ☐ Yes → Your Email Address

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

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

Please! Do not mark below this line

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We are always interested in your input in the follow-up study.
Use this space for any additional comments you may have:

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

Mail to:

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

Thank you!

Please! Do not mark below this line

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