# LTFU
## Long-Term Follow-Up

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

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

It has been a few years since we sent you our last general survey and we would now like to update your information. By completing this survey, you will bring us up-to-date on your health. The length of time to complete this survey varies, but generally takes 30-60 minutes. You can mail the completed survey to us using the enclosed envelope.

You can also complete this survey online using your smartphone, tablet or computer at:
www.stjude.org/LTFUsurveyA
Your personalized login ID is your date of birth. Your password is:
If you prefer to complete the survey with a trained interviewer over the phone, then please contact us toll free at 1-800-775-2167 or via email at LTFU@stjude.org.

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 survey relate to:

Today's date: ☐☐ / ☐☐ / 2 0 1 ☐

Person completing this survey 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

Please! Do not mark below this line

SC Edit Survey #190 Code 2163501604

St. Jude Children's Research Hospital
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Finding cures. Saving children.

## Participating Institutions

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
Children's National Medical Center
City of Hope National Medical Center
Cook Children's Hospital
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. Southwestern
U.T.M.D. Anderson Cancer Center

**Our mailing address is:**

Long-Term Follow-Up Study
St. Jude Children's Research Hospital
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Memphis, TN 38105-3678

**Toll-free phone number:**

1-800-775-2167

**e-mail:** LTFU@stjude.org

**www.stjude.org/ltfu**

## 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, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No ☒ Yes

**Example 2**

2. Have you ever taken. . .

| | No | Yes | Not sure | If yes, age at first use |
|---|---|---|---|---|
| a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil---------- | ☒ | ☐ | ☐ | |
| b. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES, such as lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil---------- | ☐ | ☒ | ☐ | 34 |

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

a.

b. mevacor

**Example 3**

3. When was this condition diagnosed?

04 Month (mm)

Year (yyyy)

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



6722501609

**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. Since this time last year, have you lost more than 10 pounds unintentionally (not due to dieting or exercise)?**

- ☐ Yes
- ☐ No
- ☐ Not sure

**A4. 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.***

**A5. 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 not currently working full or part time. . .** → ***Go to Question A7.***

**A6. 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.**

A6a. Main job title:

A6b. Please briefly describe the primary tasks in your job:

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



8326501601

**A7. 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

**A8. During the past year, how many people in this household were supported on this income?**

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

**A9. 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

**A10. Do you currently have health insurance coverage?**

- ☐ Canadian resident
- ☐ No
- ☐ Yes

# MEDICAL CARE

**B1. During the 2 year period between April 2015 and April 2017, which of the following healthcare 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 B4, next page.*
- ☐ Primary care clinician in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)
- ☐ Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)
- ☐ Other Medical specialist (e.g., endocrinologist, cardiologist, surgeon)
- ☐ Psychiatrist
- ☐ Psychologist or counselor
- ☐ Physical or occupational therapist
- ☐ Other

***If Other, please specify.***

**B2. During this 2 year period, how many times did you see a doctor?**

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

**B3. As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the doctor indicated in question B2 (during the 2 year period) were related to this previous illness?**

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

Please! Do not mark below this line

**B4. When was your MOST RECENT routine check-up where a doctor examined you and did tests to see if you had any health problems from your cancer or your cancer treatment?**

- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years but less than 5 years ago
- ☐ 5 or more years ago
- ☐ Never → *Go to Question B5.*

**B4a. Where was this check-up? *(Mark only one)***

- ☐ At a cancer survivor clinic
- ☐ At a cancer center, but not in a cancer survivor clinic
- ☐ At my primary care doctor's office
- ☐ Other

***If Other, please specify.***

**B4b. At this check-up, did your doctor give you advice about what to do to reduce risks or discuss/order medical screening tests?**

- ☐ No
- ☐ Yes
- ☐ Not sure

**B4c. When was the last time that you had a medical visit with a cancer specialist (oncologist)?**

- ☐ 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

**B4d. When was the last time you had a visit to a special clinic for <u>cancer survivors</u>?**

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

**B5. When do you plan to have your NEXT visit with a doctor in order to examine you for any health problems from your cancer or your cancer treatment?**

- ☐ Less than 1 year from now
- ☐ 1-2 years from now
- ☐ 3-4 years from now
- ☐ 5 or more years from now
- ☐ Never
- ☐ Don't know

**B6. During the PAST 12 MONTHS, how many times have you gone to a HOSPITAL EMERGENCY ROOM about your own health (This includes emergency room visits that resulted in a hospital admission)?**

☐☐ times

**B7. Do you currently have a cancer survivorship care plan and/or a summary of treatment for your cancer (records from your cancer doctor that have details about your cancer treatment and medical tests you should have to check for future health problems)?**

☐ No ☐ Yes ☐ Not sure

**B8. Does your local or primary care doctor have a copy of your cancer survivorship care plan and/or a summary of your treatment for your cancer?**

- ☐ I don't have a primary care doctor
- ☐ I have a primary care doctor but he/she does not have a copy of my cancer survivorship care plan and/or a summary of my treatment for my cancer
- ☐ Yes
- ☐ Not sure

**B9. How often do you carefully check your whole body (including the skin on your back and back of your legs) for any sign of skin cancer?**

- ☐ Once a month
- ☐ Every few months
- ☐ Every 6 months
- ☐ Every year
- ☐ Never

**B10. In the PAST 12 MONTHS, has your regular healthcare provider carefully examined your whole body for any sign of skin cancer?**

☐ No ☐ Yes ☐ Not sure

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

## New Skin Cancer Study

**We are planning a new study to help teach people about skin cancer. To assist us with planning this study, please complete these questions. If you are selected for the study, we will send you more information in the mail to help you decide if you want to participate.**

**Mark one box for each item.**

| | No | Yes | Unsure |
|---|---|---|---|
| 1. Have you ever been diagnosed with skin cancer? | ☐ | ☐ | ☐ |
| 2. Do you have a regular healthcare provider whom you have seen in the past 2 years or whom you plan to see in the next year? | ☐ | ☐ | ☐ |
| 3a. Do you have a phone that can receive text messages? | ☐ | ☐ | ☐ |
| 3b. Do you have access to a smart phone and/or an iPad? | ☐ | ☐ | ☐ |

## MEDICAL TESTS

**C1. The following questions are about medical screening tests you may have received.**

**When was the last time you had . . .**

| | 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 | I had one, but I don't recall when | I don't know if I ever had one |
|---|---|---|---|---|---|---|---|
| a. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a MUGA scan? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. An MRI of your heart (you were placed inside of a scanner, like a long tube)? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. An MRI of the head or brain? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. A test to measure your bone strength or bone mineral density (such as a DEXA scan)? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. A home blood stool test to determine whether your stool contains blood? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. Sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. An ultrasound of the thyroid gland? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| h. An ultrasound of the carotid arteries (blood vessels in the neck)? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| i. A skin exam for skin cancer by a healthcare provider? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

***For females***

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| j. A mammogram? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| k. A breast ultrasound? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| l. A breast MRI? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |
| m. A pap smear? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

***For males***

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| n. A PSA or blood test to detect prostate cancer? | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

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



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**C2. Please indicate all medicines/drugs you took *regularly* during the two-year period between April 2015 and April 2017.**

- **We are only asking about medicines/drugs that 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? No | If yes, are you currently taking? Yes |
|---|---|---|---|---|---|---|
| 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 | | | | | | |

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

**C2. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between April 2015 and April 2017.**

**- We are only asking about medicines/drugs that 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? No | If yes, are you currently taking? Yes |
|---|---|---|---|---|---|---|
| 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 | | | | | | |
| 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 | | | | | | |
| 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 | | | | | | |

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

**C2. (Cont.) Please indicate all medicines/drugs you took *regularly* during the two-year period between April 2015 and April 2017.**

- **We are only asking about medicines/drugs that 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? No | If yes, are you currently taking? Yes |
|---|---|---|---|---|---|---|
| 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. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Strattera, Aricept (donepezil), or Provigil (modafinil)---------- | ☐ | ☐ | ☐ | ☐☐ | ☐ | ☐ |
| If yes, specify the name of the drug(s) or indicate you do not know the specific name | | | | | | |
| 11. 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.**

**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 |
|---|---|---|---|---|---|
| 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 the other hearing problem(s). List the age at first occurrence for each problem separately.***

| | No | Yes, and the condition is still present | Yes, but the condition is no longer present | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|---|
| 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 |
|---|---|---|---|---|---|
| D9. Legally blind in both eyes? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| 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,*** do you have any sight?
☐ No ☐ Yes

***If yes, describe the other condition(s). List the age at first occurrence for each condition separately.***

| | No | Yes, and the condition is still present | Yes, but the condition is no longer present | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|---|
| 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 the other eye problem(s). List the age at first occurrence for each problem separately.***

**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 |
|---|---|---|---|---|---|
| D19. Stammering or stuttering speech? | ☐ | ☐ | ☐ | ☐ | |
| D20. Any other speech defects? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the other speech defect(s). List the age at first occurrence for each defect separately.***

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

## URINARY SYSTEM

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

***If yes, describe the other disorder(s). List the age at first occurrence for each disorder separately.***

## 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)? | ☐ | ☐ | ☐ | ☐ | |
| F2. A myocardial infarction (heart attack)? | ☐ | ☐ | ☐ | ☐ | |
| F3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor? | ☐ | ☐ | ☐ | ☐ | |
| F4. Coronary heart disease? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the type of problem(s). List the age at first occurrence for each problem separately.***

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

***If yes,*** do you currently take hypertension medication?
☐ No ☐ Yes

| | | | | | |
|---|---|---|---|---|---|
| F6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)? | ☐ | ☐ | ☐ | ☐ | |
| F7. Pericarditis or fluid around the heart? | ☐ | ☐ | ☐ | ☐ | |
| F8. Pericardial constriction (scarring or tightness of the sac around the heart)? | ☐ | ☐ | ☐ | ☐ | |
| F9. Stiff or leaking heart valves? | ☐ | ☐ | ☐ | ☐ | |
| F10. Blood clot in head, lung, arm, leg, or pelvis? | ☐ | ☐ | ☐ | ☐ | |
| F11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? | ☐ | ☐ | ☐ | ☐ | |

Please! Do not mark below this line

**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 |
|---|---|---|---|---|---|
| F12. High cholesterol (or triglyceride) requiring prescription medication? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| ***If yes,*** do you currently take medication for this? ☐ No ☐ Yes | | | | | |
| F13. Any other heart or circulatory problems? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the other problem(s). List the age at first occurrence for each problem separately.***

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

☐ No ☐ Yes ☐ Unsure

## 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 |
|---|---|---|---|---|---|
| G1. An overactive thyroid gland (hyperthyroid)? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G2. An underactive thyroid gland (hypothyroid)? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G3. Thyroid nodules? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G4. Swollen or enlarged thyroid gland? | ☐ | ☐ | ☐ | ☐ | ☐☐ |

**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 |
|---|---|---|---|---|---|
| G5. Diabetes that can be controlled with diet? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G6. Diabetes controlled with pills or tablets? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G7. Diabetes controlled with insulin shots? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G8. Deficiency of growth hormone? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G9. Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| ***If yes,*** do you currently take injections of growth hormone? ☐ No ☐ Yes | | | | | |
| G10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| G11. Have you ever broken a bone? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe <u>all</u> occurrences of broken bones. List the age for each individual occurrence.***

| | No | Yes, and the condition is still present | Yes, but the condition is no longer present | Not sure |
|---|---|---|---|---|
| G12. Any other hormonal problems? | ☐ | ☐ | ☐ | ☐ |

***If yes, describe the other hormonal problem(s). List the age at first occurrence for each problem separately.***

Please! Do not mark below this line

*Males* → *Go to Question H1.*

G13. **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 G15.*

G14. **FEMALES** - At what age did you last have a menstrual period naturally, without needing hormones or medication?

☐☐ **years and** ☐☐ **months old**

G15. **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. My menstrual periods are irregular but I am not using birth control pills or female hormones to regulate my periods
- ☐ e. I am currently pregnant
- ☐ f. I am not having menstrual periods naturally but I am taking birth control pills or female hormones
- ☐ g. I am not having menstrual periods naturally and I am not taking birth control pills or female hormones
- ☐ h. Other

***If Other, please describe.***

*If you selected a, b, c, d, or e* → *Go to Question H1.*

*If you selected f, g, or h* → *Go to Question G16.*

G16. **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.***

## RESPIRATORY SYSTEM

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

| | No | Yes, and the condition is still present | Yes, but the condition is no longer present | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|---|
| 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 or other chronic obstructive pulmonary disease (COPD)? | ☐ | ☐ | ☐ | ☐ | ☐☐ |
| 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 the other problem(s). List the age at first occurrence for each problem separately.***

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

## DIGESTIVE SYSTEM

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

| | No | Yes, and the condition is still present | Yes, but the condition is no longer present | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|---|
| 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. Fatty liver? | ☐ | ☐ | ☐ | ☐ | |
| I4. Any other liver trouble? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the other liver problem(s). List the age at first occurrence for each problem separately.***

| | | | | | |
|---|---|---|---|---|---|
| I5. Intestinal (colon) polyps? | ☐ | ☐ | ☐ | ☐ | |
| 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? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the other problem(s). List the age at first occurrence for each problem separately.***

## SURGICAL PROCEDURES

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

| | No | Yes | Not sure | If yes |
|---|---|---|---|---|
| J1. Amputation of an arm, leg, hand, foot? | ☐ | ☐ | ☐ | |

***If yes, specify (example: left hand, right foot). List the age for each amputation separately.***

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

***If yes, specify all surgeries of the spinal cord or spine. List the age at which each surgery occurred.***

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

***If yes, specify all joint replacements. List the age at which each joint replacement occurred.***

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



8056501601

**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 |
|---|---|---|---|---|
| J6. Other bone surgery? | ☐ | ☐ | ☐ | |

***If yes, specify all other bone surgeries. List the age at which each bone surgery occurred.***

| | No | Yes | Not sure | If yes |
|---|---|---|---|---|
| J7. Coronary artery bypass surgery? | ☐ | ☐ | ☐ | |
| J8. Pericardiectomy (stripping of the sac around the heart)? | ☐ | ☐ | ☐ | |
| J9. Heart catheterization ("heart cath")? | ☐ | ☐ | ☐ | |
| J10. Angioplasty (enlarging a heart vessel using a balloon) or stent placement to keep vessel open? | ☐ | ☐ | ☐ | |
| J11. Surgery for heart valve replacement? | ☐ | ☐ | ☐ | |
| J12. Surgery for pacemaker? | ☐ | ☐ | ☐ | |
| J13. Other heart surgery? | ☐ | ☐ | ☐ | |

***If yes, specify all other heart surgeries. List the age at which each heart surgery occurred.***

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

| | No | Yes | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|
| J14. Surgery for intestinal obstruction (blocked intestines)? | ☐ | ☐ | ☐ | |
| J15. Colostomy or ileostomy (stool going into a bag)? | ☐ | ☐ | ☐ | |
| J16. Removal of part or all of the colon | ☐ | ☐ | ☐ | |
| J17. Removal of part or all of the rectum | ☐ | ☐ | ☐ | |
| J18. Biopsy or removal of lump in thyroid gland? | ☐ | ☐ | ☐ | |
| J19. Removal of part or all of the thyroid gland? | ☐ | ☐ | ☐ | |
| J20. Removal of the spleen? | ☐ | ☐ | ☐ | |
| J21. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid? | ☐ | ☐ | ☐ | |
| J22. Breast biopsy? | ☐ | ☐ | ☐ | |
| J23. Breast-conserving or breast-sparing surgery (lumpectomy)? | ☐ | ☐ | ☐ | |
| J24. Mastectomy or removal of a breast? | ☐ | ☐ | ☐ | |

***If yes,*** was one or both breasts removed?

☐ Left only

☐ Right only

☐ Both

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



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

| | No | Yes | Not sure | If yes |
|---|---|---|---|---|
| J25. Any lung surgery? | ☐ | ☐ | ☐ | |

***If yes, specify all lung surgeries. List the age at which each lung surgery occurred.***

| | No | Yes | Not sure | If yes |
|---|---|---|---|---|
| J26. Periodontal (gum) surgery? | ☐ | ☐ | ☐ | |
| J27. Heart transplant? | ☐ | ☐ | ☐ | |
| J28. Lung transplant? | ☐ | ☐ | ☐ | |
| J29. Kidney transplant? | ☐ | ☐ | ☐ | |
| J30. Liver transplant? | ☐ | ☐ | ☐ | |
| J31. Bone marrow transplant? | ☐ | ☐ | ☐ | |
| J32. Other organ transplant? | ☐ | ☐ | ☐ | |

***If yes, specify all other organ transplants. List the age for each individual transplant.***

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

| | No | Yes | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|
| J33. Cataract surgery? | ☐ | ☐ | ☐ | |

***Males → Go to Question J37.***

| | | | | |
|---|---|---|---|---|
| J34. Removal of one ovary? | ☐ | ☐ | ☐ | |
| J35. Removal of both ovaries? | ☐ | ☐ | ☐ | |
| J36. Removal of uterus? | ☐ | ☐ | ☐ | |

***Females → Go to Question J40.***

| | | | | |
|---|---|---|---|---|
| J37. Removal of one testis? | ☐ | ☐ | ☐ | |
| J38. Removal of both testes? | ☐ | ☐ | ☐ | |
| J39. Removal of part or all of the prostate gland (prostatectomy) | ☐ | ☐ | ☐ | |
| J40. Any other surgery? | ☐ | ☐ | ☐ | |

***If yes, specify all other surgeries. List the age at which each other surgery occurred.***

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



3508501608

**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? | ☐ | ☐ | ☐ | ☐ | ☐☐ |

***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.

| | | | | | |
|---|---|---|---|---|---|
| K2. Epilepsy, repeated seizures, convulsions, or blackouts? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the problem(s) and list medications. List the age at first occurrence for each problem separately.***

***If yes,*** are you currently taking medication for this?

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

***If yes, list medications if required to control migraine or other severe headaches.***

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

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

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

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

| | No | Yes, but the condition is no longer present | Yes, and the condition is still present | Not sure | If yes, age at first occurrence |
|---|---|---|---|---|---|
| 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? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.***

**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 |
|---|---|---|---|---|---|
| K14. A stroke? | ☐ | ☐ | ☐ | ☐ | |

***If no, → Go to Question K15.***

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

| | No | Yes, but the condition is no longer present | Yes, and the condition is still present | Not sure | |
|---|---|---|---|---|---|
| a. Did the symptoms last more than 24 hours? | ☐ No | ☐ Yes | | | |
| b. Did it affect: | | | | | |
| Speech | ☐ | ☐ | ☐ | ☐ | |
| Only one side of the body | ☐ | ☐ | ☐ | ☐ | |
| Both sides of the body | ☐ | ☐ | ☐ | ☐ | |
| c. Did you lose consciousness? | ☐ No | ☐ Yes | | | |
| d. Did you have weakness or inability to move arm(s)? | ☐ | ☐ | ☐ | ☐ | |
| e. Did you have weakness or inability to move leg(s)? | ☐ | ☐ | ☐ | ☐ | |
| f. Did you have paralysis of any kind? | ☐ | ☐ | ☐ | ☐ | |

***If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.***

| | 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 the other problem(s). List the age at first occurrence for each problem separately.***

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



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## FEELINGS/EMOTIONS

**Questions L1 to L18 relate to the <u>past 7 days</u>.**

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

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

| | Not at all | A little bit | Moderately | Quite a bit | Extremely |
|---|---|---|---|---|---|
| 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. Do you currently have anxieties/fears as a result of your cancer, leukemia, tumor or similar illness, or its treatment?**

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

**L20. Do you currently have pain as a result of your cancer or similar illness, or its treatment?**

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

***Continue on next page.***

## 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?**

☐☐ **years old**

**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
- ☐ 0 drinks → ***Go to Question N7, next page.***

**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

**The following questions are referring to cigarettes containing tobacco.**

**N7. Have you smoked at least 100 cigarettes since you last provided us this information on**

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

**N8. 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 products?** ***(Mark all that apply)***

| | Never used | No longer use | Occasionally use | Regularly use |
|---|---|---|---|---|
| Chewing tobacco | ☐ | ☐ | ☐ | ☐ |
| Snuff tobacco | ☐ | ☐ | ☐ | ☐ |
| Pipes | ☐ | ☐ | ☐ | ☐ |
| Cigars | ☐ | ☐ | ☐ | ☐ |
| E-cigarettes | ☐ | ☐ | ☐ | ☐ |

***If you have never used any of these products, → Go to Question N15, next page.***

**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 | ☐ | ☐ | ☐ | ☐ | ☐ |
| E-cigarettes | ☐ | ☐ | ☐ | ☐ | ☐ |

**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, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?**

☐ No

☐ Yes

**We are interested in three types of physical activity: vigorous, moderate, and light.**
- **Vigorous activities cause large increases in breathing or heart rate.**
- **Moderate activities cause small increases in breathing or heart rate.**
- **Light activities cause no increase 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. Now, thinking about the light physical activities you do in a usual week, do you do light activities for at least 10 minutes at a time, such as a slow casual walk, or anything else that does not cause an increase in your breathing or heart rate?**

☐ No → *Go to Question N25.*

☐ Yes

**N23. How many days per week do you do these light activities for at least 10 minutes at a time?**

☐☐ Days per week

**N24. On days when you do light activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?**

☐☐☐ Minutes per day

**N25. 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

**N26. 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

**N27. Does any impairment or health problem keep you from holding a job or attending school?**

☐ No

☐ Yes

**N28. Do you currently have a driver's license?**

☐ No

☐ Yes

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

**N29. Over the last 2 years, how long (if at all) has your health limited you in each of the following activities?**

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

## DAILY ACTIVITIES

**Above, we asked you for information on activities in the last two years. This section is about your health and daily activities during the PAST 4 WEEKS. Please try to answer every question as accurately as you can.**

**O1. In general, would you say your health is:**

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

**O2. Compared to one year ago, how would you rate your health in general now?**

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

**O3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

| | Yes, limited a lot | Yes, limited a little | No, not limited at all |
|---|---|---|---|
| a. Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports | ☐ | ☐ | ☐ |
| b. Moderate Activities, such as moving a table, bowling, or playing golf | ☐ | ☐ | ☐ |
| c. Lifting or carrying groceries | ☐ | ☐ | ☐ |
| d. Climbing several flights of stairs | ☐ | ☐ | ☐ |
| e. Climbing one flight of stairs | ☐ | ☐ | ☐ |
| f. Bending, kneeling, or stooping | ☐ | ☐ | ☐ |
| g. Walking more than a mile | ☐ | ☐ | ☐ |
| h. Walking several hundred yards | ☐ | ☐ | ☐ |
| i. Walking one hundred yards | ☐ | ☐ | ☐ |
| j. Bathing or dressing yourself | ☐ | ☐ | ☐ |

**O4. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| a. Cut down on the amount of time you spent on work or other activities | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. Accomplished less than you would like | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. Were limited in the kind of work or other activities | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. Had difficulty performing the work or other activities (for example, it took extra effort) | ☐ | ☐ | ☐ | ☐ | ☐ |

Please! Do not mark below this line

**O5. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| a. Cut down on the amount of time you spent on work or other activities | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. Accomplished less than you would like | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. Did work or activities less carefully than usual | ☐ | ☐ | ☐ | ☐ | ☐ |

**O6. During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?**

☐ Not at all ☐ Quite a bit

☐ Slightly ☐ Extremely

☐ Moderately

**O7. How much bodily pain have you had during the PAST 4 WEEKS?**

☐ None ☐ Moderate

☐ Very mild ☐ Severe

☐ Mild ☐ Very severe

**O8. 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

# HEALTH AND WELL-BEING

**P1. These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please mark the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS. . .**

| | All of the time | Most of the time | Some of the time | A little of the time | None of the time |
|---|---|---|---|---|---|
| a. Did you feel full of life? | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. Have you been very nervous? | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. Have you felt so down in the dumps that nothing could cheer you up? | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. Have you felt calm and peaceful?. | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. Did you have a lot of energy? | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. Have you felt downhearted and depressed? | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. Did you feel worn out? | ☐ | ☐ | ☐ | ☐ | ☐ |
| h. Have you been happy? | ☐ | ☐ | ☐ | ☐ | ☐ |
| i. Did you feel tired? | ☐ | ☐ | ☐ | ☐ | ☐ |

**P2. During the PAST 4 WEEKS, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

☐ All of the time ☐ A little of the time

☐ Most of the time ☐ None of the time

☐ Some of the time

**P3. How TRUE or FALSE is each of the following statements for you?**

| | Definitely true | Mostly true | Don't know | Mostly false | Definitely false |
|---|---|---|---|---|---|
| a. I seem to get sick a little easier than other people | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. I am as healthy as anybody I know | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. I expect my health to get worse | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. My health is excellent | ☐ | ☐ | ☐ | ☐ | ☐ |

Please! Do not mark below this line

## PROBLEM SOLVING

**Q. Below is a list of statements that describe problems people can have. We would like to know if you have had any of these problems over the PAST 6 MONTHS. Please complete all items. Please think about yourself as you read these statements and mark one response on each line.**

| | Never a problem | Sometimes a problem | Often a problem |
|---|---|---|---|
| 1. I get upset easily | ☐ | ☐ | ☐ |
| 2. It takes me longer to complete my work | ☐ | ☐ | ☐ |
| 3. I am disorganized | ☐ | ☐ | ☐ |
| 4. I forget instructions easily | ☐ | ☐ | ☐ |
| 5. I have problems completing my work | ☐ | ☐ | ☐ |
| 6. I have difficulty recalling things I had previously learned (e.g., names, places, events, activities) | ☐ | ☐ | ☐ |
| 7. I get frustrated easily | ☐ | ☐ | ☐ |
| 8. My mood changes frequently | ☐ | ☐ | ☐ |
| 9. I have trouble finding things in my bedroom, closet or desk | ☐ | ☐ | ☐ |
| 10. I forget what I am doing in the middle of things | ☐ | ☐ | ☐ |
| 11. I have problems getting started on my own | ☐ | ☐ | ☐ |
| 12. I am easily overwhelmed | ☐ | ☐ | ☐ |
| 13. I have trouble doing more than one thing at a time | ☐ | ☐ | ☐ |
| 14. My desk/workspace is a mess | ☐ | ☐ | ☐ |
| 15. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.) | ☐ | ☐ | ☐ |
| 16. I have trouble prioritizing my activities | ☐ | ☐ | ☐ |
| 17. I read slowly | ☐ | ☐ | ☐ |
| 18. I am slower than others when completing my work | ☐ | ☐ | ☐ |
| 19. I have trouble solving math problems in my head | ☐ | ☐ | ☐ |
| 20. I don't work well under pressure | ☐ | ☐ | ☐ |
| 21. I have trouble staying on the same topic when talking | ☐ | ☐ | ☐ |
| 22. I have a messy closet | ☐ | ☐ | ☐ |
| 23. People say I am easily distracted | ☐ | ☐ | ☐ |
| 24. I have angry outbursts | ☐ | ☐ | ☐ |
| 25. I have a short attention span | ☐ | ☐ | ☐ |
| 26. I overreact emotionally | ☐ | ☐ | ☐ |
| 27. I have trouble organizing work | ☐ | ☐ | ☐ |
| 28. I overreact to small problems | ☐ | ☐ | ☐ |
| 29. I have problems organizing activities | ☐ | ☐ | ☐ |
| 30. I have emotional outbursts for little reason | ☐ | ☐ | ☐ |
| 31. I leave the bathroom a mess | ☐ | ☐ | ☐ |
| 32. I react more emotionally to situations than my friends | ☐ | ☐ | ☐ |
| 33. I leave my room or home a mess | ☐ | ☐ | ☐ |

**If you answered "Sometimes" or "Often" to any of the questions in Section Q, to what extent do the problems you may have checked interfere with your ability to function?**

| | Never | Sometimes | Often | Not applicable |
|---|---|---|---|---|
| 1. In your home | ☐ | ☐ | ☐ | ☐ |
| 2. At your job | ☐ | ☐ | ☐ | ☐ |
| 3. In social situations | ☐ | ☐ | ☐ | ☐ |
| 4. In educational activities | ☐ | ☐ | ☐ | ☐ |

## OTHER ISSUES

**Please rate how concerned you are about the following:**

| | Very concerned | Somewhat concerned | Concerned | Not very concerned | Not at all concer |
|---|---|---|---|---|---|
| R1. Your future health | ☐ | ☐ | ☐ | ☐ | ☐ |
| R2. Your ability to have children | ☐ | ☐ | ☐ | ☐ | ☐ |
| R3. Developing a cancer | ☐ | ☐ | ☐ | ☐ | ☐ |
| R4. Your ability to get health insurance | ☐ | ☐ | ☐ | ☐ | ☐ |
| R5. Your ability to get life insurance | ☐ | ☐ | ☐ | ☐ | ☐ |
| R6. Your ability to cover expenses for health care | ☐ | ☐ | ☐ | ☐ | ☐ |
| R7. Your ability to cover expenses for prescribed medicine | ☐ | ☐ | ☐ | ☐ | ☐ |
| R8. Any other issues | ☐ | ☐ | ☐ | ☐ | ☐ |

***Please specify.***

Please! Do not mark below this line

## CANCER, LEUKEMIA, OR TUMOR

**S1.**

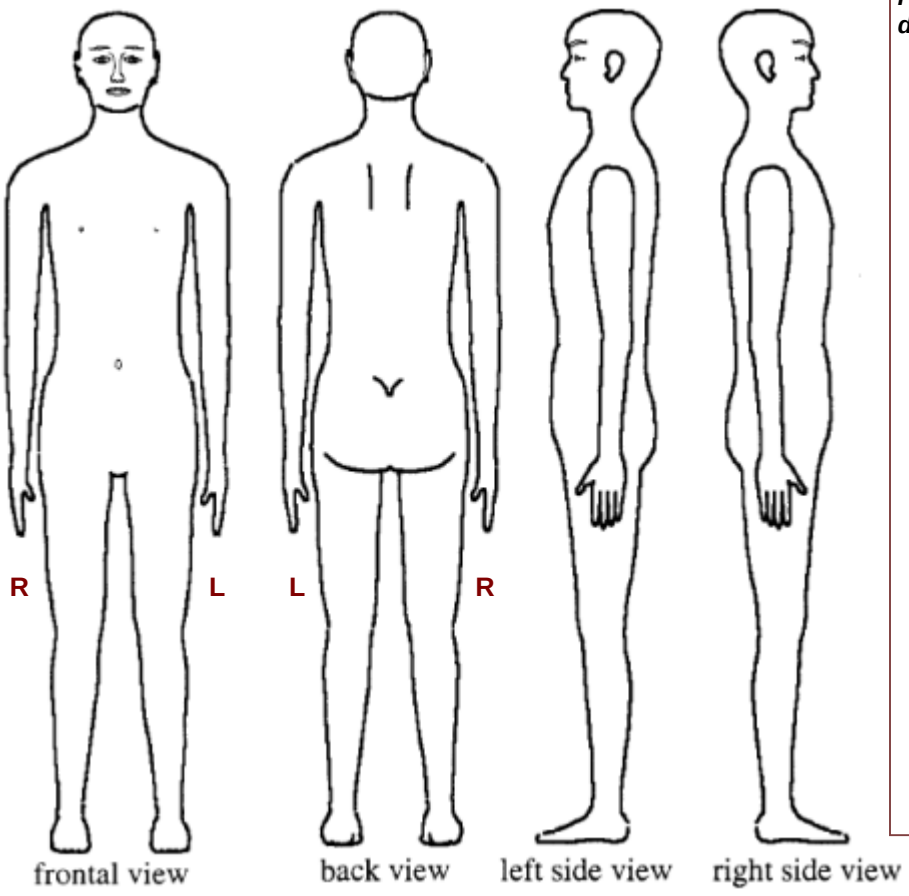
☐ No → *Go to Question T1, page 29.*

☐ Yes

**S2. What was the name of this disease?**

**S3. Where was it located? (Example: right upper arm, left ear)**

**If the condition in item S2 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.**




**S4. Where was this diagnosed?**

| |
|---|
| Doctor's name |
| Hospital or clinic |
| Address |
| City, State, Zip code |

**S5. Was this a:**

☐ Recurrence of original diagnosis

☐ New cancer, leukemia, tumor, or similar illness

☐ Don't know

**Date of Recurrence or New Diagnosis:**

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

***Please use this space to provide any additional details on tumor location.***

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



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**S6.**

☐ No → *Go to Question T1, next page.*

☐ Yes

**S7. What was the name of this disease?**

**S8. Where was it located? (Example: right upper arm, left ear)**

**S9. Where was this diagnosed?**

| |
|---|
| Doctor's name |
| Hospital or clinic |
| Address |
| City, State, Zip code |

**S10. Was this a:**

☐ Recurrence of original diagnosis

☐ New cancer, leukemia, tumor, or similar illness

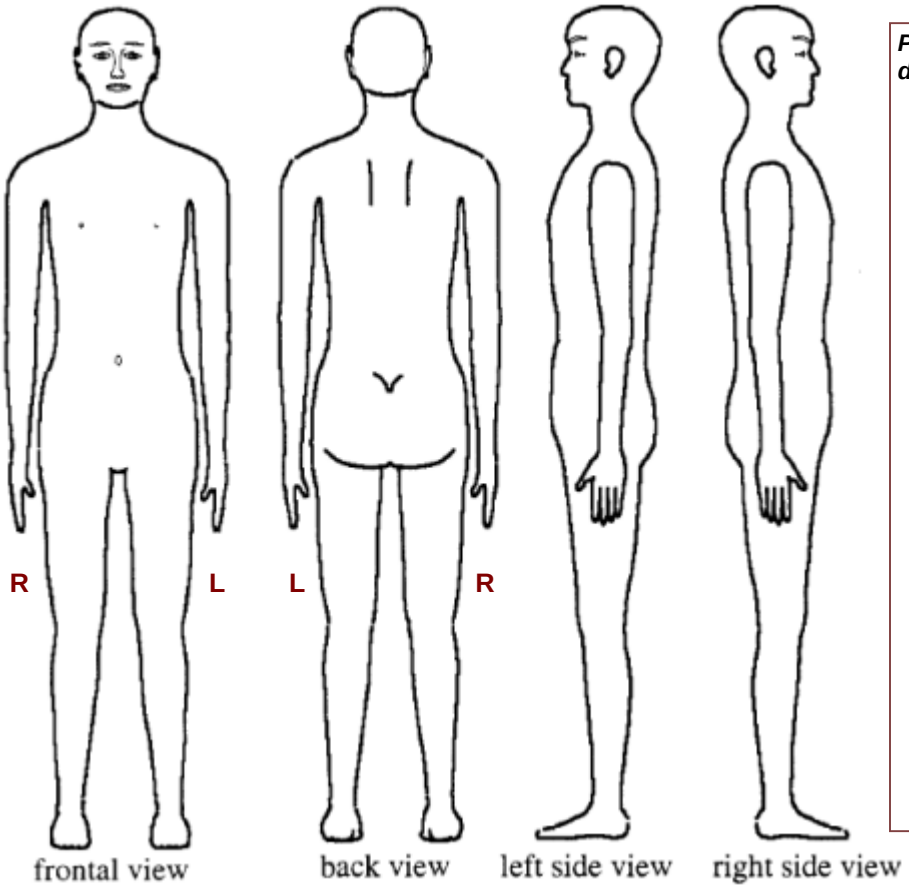
☐ Don't know

**Date of Recurrence or New Diagnosis:**

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

**If the condition in item S7 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.**

**Please use a separate sheet of paper for additional cancers**




***Please use this space to provide any additional details on tumor location.***

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

# TREATMENT FOR NEW OR RECURRENT TUMOR OR CANCER

**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.**

**T1.** _____

☐ No → *Go to Question T2.*

☐ Yes

☐ Not sure

**T1a. 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)**

**T1b. Please indicate the reason for radiation.**

**T1c. Where did you receive the radiation treatment?**

| |
|---|
| Hospital or clinic |
| Address |
| City, State, Zip code |
| Doctor's name |

**T2.** _____

☐ No → *Go to Question U1, next page.*

☐ Yes

☐ Not sure

**T2a. 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)**

**T2b. Please indicate the reason for chemotherapy.**

**T2c. Where did you receive the chemotherapy treatment?**

| |
|---|
| Hospital or clinic |
| Address |
| City, State, Zip code |
| Doctor's name |

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

# HOSPITALIZATIONS

**We are interested in any admissions to the hospital for illness, surgical, or diagnostic procedures, including psychiatric/mental health hospitalization or short stays of 24 hours or less that you may have had in the last 12 months. DO NOT INCLUDE PREGNANCY RELATED ADMISSIONS or EMERGENCY ROOM VISITS.**

**U1. Have you been admitted to a hospital in the last 12 months?**

☐ No → *Go to Section V, next page.*

☐ Yes

**U2. How many times have you been admitted to a hospital in the last 12 months?** ☐☐

**U3. What was the reason for the first hospitalization?**

**U3a. What procedures/surgeries were performed?**

**U3b. Where were you hospitalized?**

| |
|---|
| Hospital |
| Address |
| City, State, Zip code |
| Doctor's name |

**U3c. Date of first hospitalization:**

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

**U4. What was the reason for the second hospitalization?**

**U4a. What procedures/surgeries were performed?**

**U4b. Where were you hospitalized?**

| |
|---|
| Hospital |
| Address |
| City, State, Zip code |
| Doctor's name |

**U4c. Date of second hospitalization:**

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

**Please use a separate sheet of paper for additional hospitalizations**

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

# PREGNANCY AND OFFSPRING

**Female**

**V1.**

☐ No → *Go to page 32.*

☐ Yes

**V2. Are you currently pregnant?**

☐ No

☐ Yes

*Continue to Question V5 below.*

**Male**

**V3.**

☐ No → *Go to page 32.*

☐ Yes

**V4. Is she currently pregnant?**

☐ No

☐ Yes

*Continue to Question V5 below.*

**V5.**

**Pregnancy outcome**

| | Live birth | Stillbirth | Miscarriage | Medical abortion | Currently pregnant | 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. . . . . | ☐ | ☐ | ☐ | ☐ | ☐ | ☐☐ | ☐☐ | ☐☐ |
| Pregnancy 6. . . . . | ☐ | ☐ | ☐ | ☐ | ☐ | ☐☐ | ☐☐ | ☐☐ |
| Pregnancy 7. . . . . | ☐ | ☐ | ☐ | ☐ | ☐ | ☐☐ | ☐☐ | ☐☐ |
| Pregnancy 8. . . . . | ☐ | ☐ | ☐ | ☐ | ☐ | ☐☐ | ☐☐ | ☐☐ |

**Please attach a separate sheet of paper, if more than 8 pregnancies**

## GENETIC CONDITIONS

**Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions that you have. 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.**

**W1a. Have you ever been told by a doctor that you have. . .**

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

***If yes, describe this disorder.***

**W1b. Has anyone in your immediate family (blood relatives only) ever had any of the conditions in Question W1a? *(Mark all that apply)***

| | ***What conditions?*** |
|---|---|
| ☐ Mother → | |
| ☐ Father → | |
| ☐ Full brother → | |
| ☐ Full sister → | |
| ☐ 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.**

**W2. Have you ever had genetic counseling for cancer risk?**

☐ No

☐ Yes

***Continue on next page.***

**W3a. To the best of your knowledge, were you born with. . .**

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

***If other, please specify.***

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

***If other, please specify.***

**W3b. Has anyone in your immediate family (blood relatives only) ever had any of the conditions in Question W3a?** ***(Mark all that apply)***

***What conditions?***

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

**W4. Has anyone in your immediate family (blood relatives only) ever had cancer?** ***(Mark all that apply)***

***What types?***

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

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

**1. 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.

**2. 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.

**3. 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.

**4. 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).

**5. 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.

**6. 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.

**7. 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.

! Sign Here

_____
Printed name of research participant

_____
Signature of research participant or legal guardian

_____
Date

Fill in 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.

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

1. **Do you use a cell phone?**

☐ Yes ☐ No → *Go to question 3.*

**1a. Would you be willing to send/receive study-related texts?**

☐ Yes ☐ No ☐ My phone is not text capable

2. **Do you use a "smartphone" that can access the internet or download "apps" (e.g. iPhone, Android, Blackberry, Windows)?**

☐ Yes ☐ No

3. **Which of the following types of devices do you use to access the internet?** ***(Mark all that apply)***

☐ Computer or laptop

☐ Tablet (iPad or similar)

☐ Smartphone

☐ Other, specify: _____

☐ I don't access the internet

4. **If available in the future, how likely would you be to use a LTFU Study app on your smartphone, tablet, or computer to do the following:**

| | Very likely | Possibly | Very unlikely |
|---|---|---|---|
| a. Read study newsletters? . . . . . | ☐ | ☐ | ☐ |
| b. Access health information? . . . . . | ☐ | ☐ | ☐ |
| c. Answer future questionnaires? . . . . . | ☐ | ☐ | ☐ |
| d. Participate in electronic health monitoring studies (e.g. using monitors of heart rate, activity, or other health-related measures)? . . . . . | ☐ | ☐ | ☐ |

Do you have an email address we could use to contact you? ☐ No ☐ Yes →

Your Email Address:

**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: | Cell phone: | Home phone: | Work phone: |

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 | |
| City: | | State: | |
| Zip code: | Cell phone: | Home phone: | Work phone: |

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



0877501604

**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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