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

SJLIFE
Home Survey

Finding cures. Saving children.

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

☐ Self ☐ Parent ☐ Other: _____

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

Our mailing address is:
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Memphis, TN 38105-3678

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1-800-775-2167

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Please! Do not mark below this line

Survey #240

4294091515

04/10/2018 11:14:42 AM

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:

CORRECT

Grape

INCORRECT

MARKING EXAMPLES

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

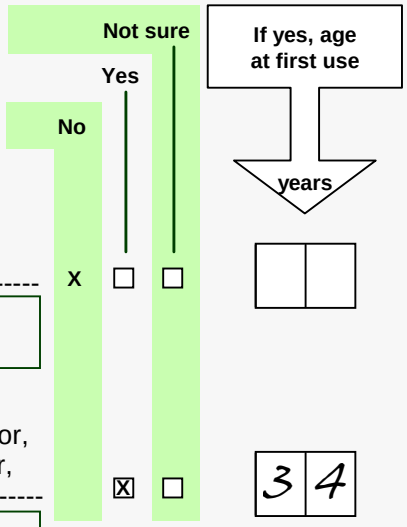
EXAMPLE 1

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

A1. What is your date of birth?

☐☐ / ☐☐ / ☐☐☐☐

m m d d y y y y

A2. What is your sex?

☐ Male

☐ Female

A3. To the nearest inch, what is your current height without shoes?

☐ feet, and ☐☐ inches

A4. To the nearest pound, what is your current weight without shoes?

☐☐☐ pounds

A4a. Since this time last year, have you lost more than 10 pounds unintentionally (not due to dieting or exercise)?

☐ Yes

☐ No

☐ Not sure

A5. To which one of the following groups do you belong?

☐ White

☐ Black

☐ American Indian or Alaskan Native

☐ Asian

☐ Pacific Islander

☐ Other

Specify

A5a. Are you Hispanic?

☐ No

☐ Yes

A6. Are you a twin or born of a multiple birth?

☐ No → *Go to Question A7.*

☐ Yes

A6a. If yes, which type of multiple are you?

☐ Identical twin

☐ Fraternal (non-identical) twin, same sex

☐ Fraternal (non-identical) twin, opposite sex

☐ Not sure what type of twin, same sex

☐ More than twin

Specify

A7. Were you adopted?

☐ No

☐ Yes

A8. How many full brothers and sisters (living or dead) do/did you have? Include only those brothers and sisters who have the same birth (biological) mother and father as you.

☐☐

A9. Concerning your current residence, do you: ***(Mark all that apply)***

☐ Own your residence

☐ Rent

☐ Live with parents

☐ Other

Specify

Please! Do not mark below this line

Medical Care

The next questions are about health care received during the last two years.

B1. During the last two years, 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 B7, 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 last two years, where did you receive your health care?
(Mark all that apply)

- ☐ Doctor's office
- ☐ Oncology (cancer) center or clinic
- ☐ Other type of clinic
- ☐ Hospital
- ☐ Emergency Room or Urgent Care Center
- ☐ Long-term follow-up clinic
- ☐ Other

Specify

B3. During this last two years, how many times did you see a physician?

- ☐ 0 times → *Go to Question B5a.*
- ☐ 1 - 2 times
- ☐ 3 - 4 times
- ☐ 5 - 6 times
- ☐ 7 - 10 times
- ☐ 11 - 20 times
- ☐ More than 20 times

B4. As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the physician indicated in question B3 (during the past 2 years) were related to this previous illness?

- ☐ 0 visits
- ☐ 1 - 2 visits
- ☐ 3 - 4 visits
- ☐ 5 - 6 visits
- ☐ 7 - 10 visits
- ☐ 11 - 20 visits
- ☐ More than 20 visits

B5a. During this 2 year period, how often did you telephone a doctor's office, regarding an illness or a medical condition you may have had?

- ☐ 0 times
- ☐ 1 - 2 times
- ☐ 3 - 4 times
- ☐ 5 - 6 times
- ☐ 7 - 10 times
- ☐ 11 - 20 times
- ☐ More than 20 times

B5b. Of these telephone contacts, how many were to St. Jude?

☐☐

B6. During this 2 year period, how many times were you admitted to any hospital?

☐☐

Please! Do not mark below this line

B7. 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 B7d.*

B7a. 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.

B7b. At this check-up, did your doctor give you advice about what to do to reduce risks or discuss medical screening tests?

- ☐ No
- ☐ Yes
- ☐ Not sure

B7c. At this check-up, did your doctor order medical screening tests?

- ☐ No
- ☐ Yes
- ☐ Not sure

B7d. 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

B7e. When was the last time you had a visit to a special clinic for cancer survivors?

- ☐ 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

B7f. 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

B7g. 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

Please! Do not mark below this line

B7h. 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

B7i. 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

B7j. 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

B7k. In the <u>past 12 months</u>, has your regular healthcare provider carefully examined your whole body for any sign of skin cancer?

☐ No ☐ Yes ☐ Not sure

B8. Please indicate all medicines/drugs you took *regularly* during the <u>last two years</u>.

- 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? No	If yes, are you currently taking? Yes
1. BIRTH CONTROL MEDICATIONS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil, Depo Provera ----------	☐	☐	☐	☐☐ 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						

Please! Do not mark below this line

B8. (Cont) Please indicate all medicines/drugs you took *regularly* during the last two years.

- **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? No	If yes, are you currently taking? Yes
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)	☐	☐	☐	years	☐	☐
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						
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

B8. (Cont) Please indicate all medicines/drugs you took *regularly* during the last two years.

- **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? 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----------	☐	☐	☐	☐☐ years	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
10. MEDICATIONS FOR TREATMENT OF LOW BONE MINERAL DENSITY (OSTEOPOROSIS/OSTEOPENIA) such as Fosamax (alendronate), Boniva (ibandronate), Actonel (risedronate), or Evista (raloxifene)----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
11. MEDICATIONS TO CORRECT LOW BLOOD LEVELS OF POTASSIUM, MAGNESIUM, PHOSPHOROUS, OR BICARBONATE such as KCl, KPhos, NeutraPhos, or Bicitra----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
12. 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						
13. 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

B9. Please list all over the counter medications (NOT prescribed by a doctor) which you took *regularly* during the last two years.

We are only asking about medications which you took consistently for more than one month, or for 30 days or more in a year. Include pills, syrups, injections, patches, or creams.

B10. Please list all supplements which you took *regularly* during the last two years.

We are only asking about medicines which you took consistently for more than one month, or for 30 days or more in a year. Include pills, syrups, injections, patches, or creams.

Continue on next page.

Medical Conditions

The next series of questions relate to medical conditions that have ever occurred in your lifetime.

Please indicate, by marking the box (either "No", "Yes", or "Not sure") if a doctor or other health care professional has told you that you have or have had any of the following conditions. In addition, please give your approximate age when the condition first occurred. (If more than one occurrence, please give age at first occurrence.)

Because we need definite responses, it is very important to mark an answer for each question, even if you have never had that condition. Please do not leave any questions blank (unmarked).

DENTAL HEALTH

Questions C1 to C19 are about your general dental health and any dental care you may have received.

In addition to the above instructions, if you answered either "Yes" response to any of the items below, please also mark "Yes" or "No" to whether you have received this care in the last 2 years.

Have you ever. . .

	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)	Have you received care for this in the last two years? Yes	No
C1. Had one or more missing teeth because they did not develop?	☐	☐	☐	☐		☐	☐
C2. Had a lack of or decreased amount of enamel on surface of teeth (hypoplasia)?	☐	☐	☐	☐		☐	☐
C3. Had abnormal shaped (small or malformed) teeth?	☐	☐	☐	☐		☐	☐
C4. Had abnormal root development?	☐	☐	☐	☐		☐	☐
C5. Had difficulty in producing saliva (dry mouth) that required treatment such as artificial saliva?	☐	☐	☐	☐		☐	☐
C6. Had severe gingivitis or gum disease requiring surgery or deep cleaning?	☐	☐	☐	☐		☐	☐
C7. Had root canal therapy?	☐ No	☐ Yes	☐ Not Sure			☐	☐
C8. Had more than 5 cavities?	☐ No	☐ Yes	☐ Not Sure				
C9. Lost 6 or more teeth due to decay or gum disease?	☐ No	☐ Yes	☐ Not Sure				
C10. Worn a dental bridge (for missing or removed teeth)?	☐	☐	☐	☐		☐	☐
C11. Worn removable dentures (complete or partial upper or lower or both)?	☐	☐	☐	☐		☐	☐
C12. Worn a prosthesis to lift your palate to improve the quality of your voice?	☐	☐	☐	☐		☐	☐
C13. Had other dental treatment or surgery?	☐ No	☐ Yes	☐ Not Sure			☐	☐

If yes, explain type of procedure.

C14. Had any other dental problems?	☐	☐	☐	☐		☐	☐

If yes, explain type of procedure.

Please! Do not mark below this line

C15. Have you ever had dental braces?

☐ No ☐ Yes ☐ Don't know

C16. Do you currently have dental insurance?

☐ No ☐ Yes ☐ Don't know

C17. Have you visited the dentist or a dental clinic within the past year for any reason?

☐ No ☐ Yes ☐ Don't know

C18. Have you had your teeth cleaned by the dentist or dental hygienist within the past year?

☐ No ☐ Yes ☐ Don't know

C19. Do you have problems finding a dentist to help with your dental care because of your previous cancer or similar illness?

☐ No ☐ Yes ☐ Don't know

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

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)
D8. Legally blind in only one eye?	☐	☐	☐	☐	
If yes, do you have any sight in this eye? ☐ No ☐ Yes					
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 the other condition(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 (years)
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 (years)
D19. Stammering or stuttering?	☐	☐	☐	☐	
D20. Any other speech defects?	☐	☐	☐	☐	

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

D21. Abnormal sense of taste?	☐	☐	☐	☐	
D22. Loss of taste lasting for 3 months or more?	☐	☐	☐	☐	
D23. Loss of 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. Protein in your urine?	☐	☐	☐	☐	
E6. Urinary incontinence?	☐	☐	☐	☐	
E7. 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.

HORMONAL SYSTEMS

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

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

If yes, do you currently take injections of growth hormone?
☐ No ☐ Yes

F10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?	☐	☐	☐	☐	
F11. Have you ever broken a bone?	☐	☐	☐	☐	

If yes, describe all occurrences of broken bone(s). List the age for each individual occurrence.

F12. 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

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

Males → Go to Question G1.

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 to induce menstruation?

☐☐ **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. 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 G1.

If you selected f, g, or h → 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.

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 the type of problem(s). List the age at first occurrence for each problem separately.

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

If yes, do you currently take hypertension medication?

☐ No ☐ Yes

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.

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)
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

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

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

G14. Has anyone in your immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?

☐ No ☐ Yes ☐ Unsure

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 (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 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.

Continue on next page.

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.

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 the liver problem(s). List the age at first occurrence for each problem separately.

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. Stricture (narrowing or scarring) of the small or large intestine?	☐	☐	☐	☐	
I10. 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, age at first occurrence (years)
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.

J6. Other bone surgery?	☐	☐	☐	

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

J7. Coronary artery bypass surgery?	☐	☐	☐	

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 procedure.

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)
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.

	No	Yes	Not sure	If yes, age at first occurrence (years)
J14. Surgery to repair a fistula (an abnormal connection between the intestine or rectum and other structures)?	☐	☐	☐	
J15. Surgery for intestinal obstruction (blocked intestines)?	☐	☐	☐	
J16. Colostomy or ileostomy (stool going into a bag)?	☐	☐	☐	
J17. Removal of part or all of the colon	☐	☐	☐	
J18. Removal of part or all of the rectum	☐	☐	☐	
J19. Biopsy or removal of lump in thyroid gland?	☐	☐	☐	
J20. Removal of part or all of the thyroid gland?	☐	☐	☐	
J21. Removal of the spleen?	☐	☐	☐	
J22. Bladder, ureter, or kidney surgery?	☐	☐	☐	
J23. Removal of all or part of a kidney?	☐	☐	☐	
J24. Liver or gall bladder surgery?	☐	☐	☐	
J25. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid?	☐	☐	☐	
J26. Breast biopsy?	☐	☐	☐	
J27. Breast-conserving or breast-sparing surgery (lumpectomy)?	☐	☐	☐	
J28. 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

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

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)
J29. Any lung surgery?	☐	☐	☐	

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

	No	Yes	Not sure	If yes, age at first occurrence (years)
J30. Periodontal (gum) surgery? .	☐	☐	☐	
J31. Heart transplant?	☐	☐	☐	
J32. Lung transplant?	☐	☐	☐	
J33. Kidney transplant?	☐	☐	☐	
J34. Liver transplant?	☐	☐	☐	
J35. Bone marrow transplant? . . .	☐	☐	☐	
J36. Other organ transplant?	☐	☐	☐	

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

	No	Yes	Not sure	If yes, age at first occurrence (years)
J37. Cataract surgery?	☐	☐	☐	

Males → Go to Question J42.

	No	Yes	Not sure	If yes, age at first occurrence (years)
J38. Removal of one ovary?.	☐	☐	☐	
J39. Removal of both ovaries?. . . .	☐	☐	☐	
J40. Removal of uterus?.	☐	☐	☐	
J41. Surgery of the vagina?.	☐	☐	☐	

Females → Go to Question J45.

	No	Yes	Not sure	If yes, age at first occurrence (years)
J42. Removal of one testis?.	☐	☐	☐	
J43. Removal of both testes?.	☐	☐	☐	
J44. Removal of part or all of the prostate gland (prostatectomy)	☐	☐	☐	
J45. Any other surgery?	☐	☐	☐	

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

Continue on next page.

Please! Do not mark below this line

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 (years)
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 this problem(s). List the age at first occurrence for each problem separately.

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

If yes, name of medications

Date of last seizure
M M / D D / Y Y Y Y

	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)
K3. Migraine?	☐	☐	☐	☐	
K4. Other severe headaches? . . .	☐	☐	☐	☐	
K5. Other repeated headaches?	☐	☐	☐	☐	

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

K6. 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.

K7. Tremors or problems with movements?	☐	☐	☐	☐	
K8. Problems chewing or swallowing solids or liquids? . .	☐	☐	☐	☐	
K9. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
K10. Prolonged pain in arms or legs.	☐	☐	☐	☐	
K11. Prolonged pain in back	☐	☐	☐	☐	
K12. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
K13. Weakness or inability to move arm(s)?	☐	☐	☐	☐	

Please! Do not mark below this line

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

Have you <u>ever</u> 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)
K14. Weakness or inability to move leg(s)?	☐	☐	☐	☐	☐☐
K15. Paralysis of any kind?	☐	☐	☐	☐	☐☐

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

K16. Stroke?	☐	☐	☐	☐	☐☐

If no → Go to K18.

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

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

Did the stroke affect:

b. Speech	☐	☐	☐	☐
c. Balance and coordination	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐

d. Did you lose consciousness?
☐ No ☐ Yes

e. Did you experience sensory loss (vision, taste, smell)?	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐
f. Did you have weakness or inability to move arm(s)?	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐
g. Did you have weakness or inability to move leg(s)?	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure
h. Did you have paralysis of any kind?	☐	☐	☐	☐
Only one side of the body	☐	☐	☐	☐
Both sides of the body	☐	☐	☐	☐

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

K17. In your lifetime, how many strokes have you had? ☐☐

					If yes, age at first occurrence (years)
K18. Any other brain or nervous system problems?	☐	☐	☐	☐	☐☐

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

K19. Do you have any driving restrictions because of brain or nervous system problems (such as seizures)?
☐ No
☐ Yes, but I am able to drive
☐ Yes, I am unable to drive
☐ Unsure

K20. Do you have any work restrictions because of brain or nervous system problems (such as seizures)?
☐ No
☐ Yes, but I am able to work
☐ Yes, I am unable to work
☐ Unsure

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMORS

L1. At any time following your original diagnosis, were you diagnosed with another cancer, leukemia, tumor, or similar illness? (Include any relapse or recurrence of your original diagnosis).

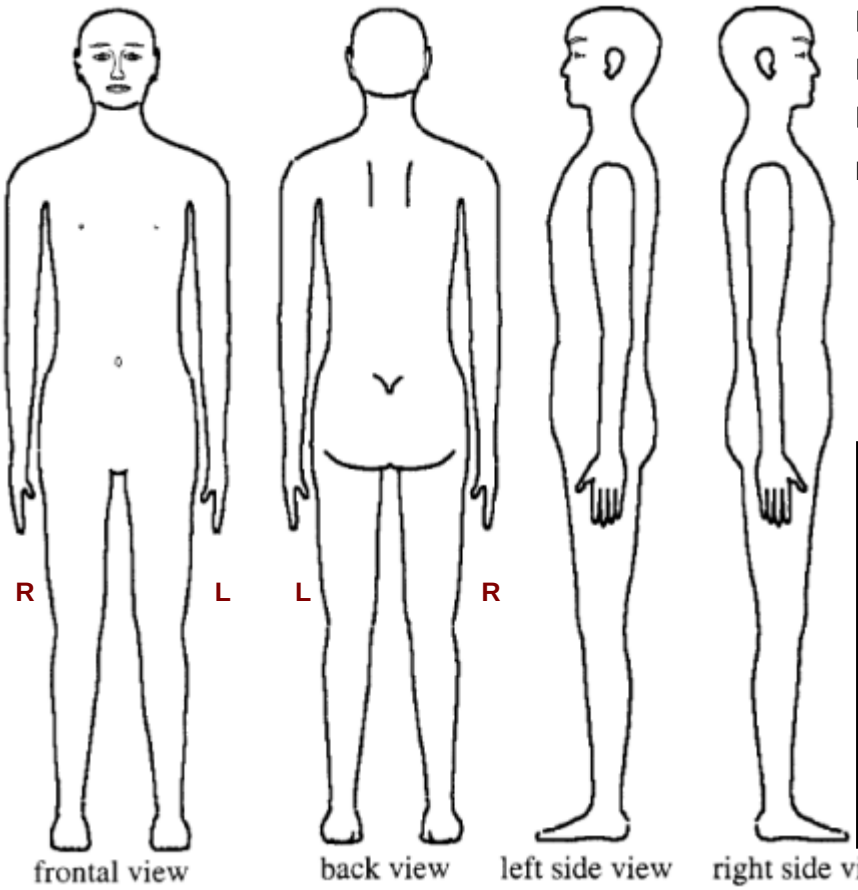
☐ No → *Go to Question M1, page 22.*

☐ Yes

L2. What was the name of this disease?

L3. Where was it located? (Example: right upper arm, left ear)

If the condition in item L2 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.



L4. Did you have treatment for this disease?

☐ No →

☐ Yes → **L4a. What treatments did you receive?** ***(Mark all that apply)***

☐ Chemotherapy

☐ Radiation therapy

☐ Surgery

L5. Where was this diagnosed?

L6. 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)**

L7. Have you had any additional cancers, leukemias, tumors, or similar illnesses after this second one?

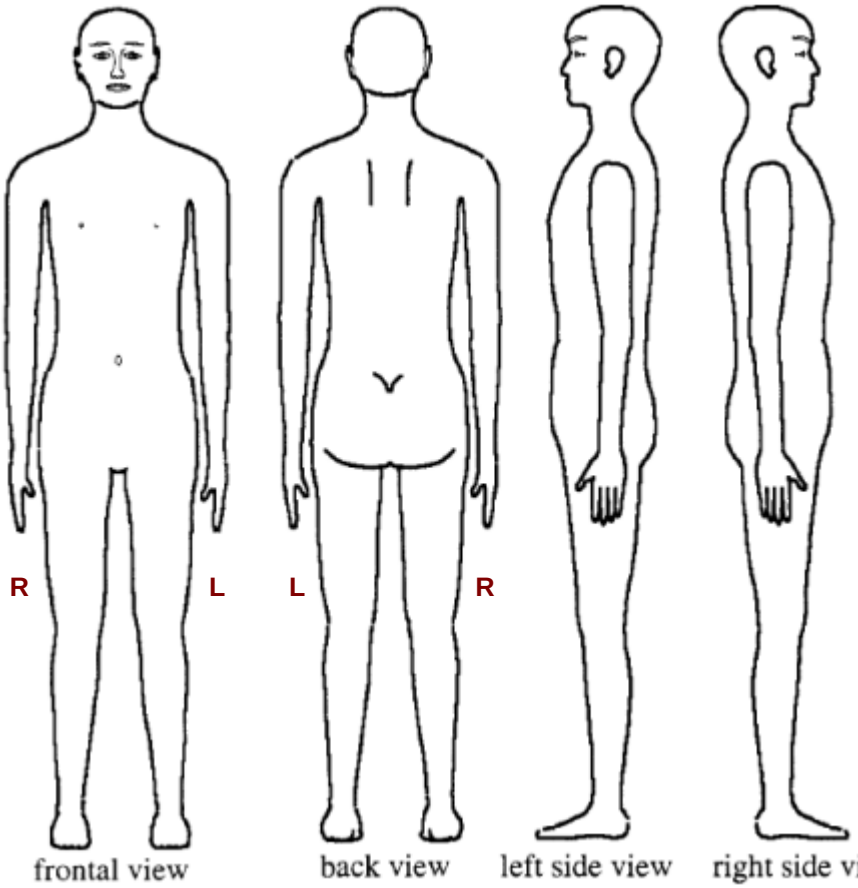
☐ No → *Go to Question M1, next page.*

☐ Yes

L8. What was the name of this disease?

L9. Where was it located? (Example: right upper arm, left ear)

If the condition in item L8 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.



L10. Did you have treatment for this disease?

☐ No → *Skip L10a and go to Question L11.*

☐ Yes → **L10a. What treatments did you receive?** ***(Mark all that apply)***

☐ Chemotherapy

☐ Radiation therapy

☐ Surgery

L11. Where was this diagnosed?

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

L12. 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 use a separate sheet of paper for additional cancers

Please! Do not mark below this line

OFFSPRING/PREGNANCY HISTORY

M1. Have you ever been sexually active (had sexual intercourse)?

☐ No → *Go to Question N1, page 24.*

☐ Yes

M2. Are you currently sexually active?

☐ No

☐ Yes

M3. Have you or your partner had:
(Mark all that apply)

☐ A vasectomy → ***At what age?*** ☐☐

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

M4. Was there ever a period in your life when you and a partner tried for one year or more to become pregnant, without success?

☐ No

☐ Yes

M5. Have you and a partner ever become pregnant?

☐ No → *Go to Question N1, page 24.*

☐ Yes

M6. Including live births, stillbirths, miscarriages, and abortions, how many times have you become pregnant or had a woman become pregnant by you?

☐☐ **times**

Continue on next page.

Female

M7. Have you ever had any pregnancies?

☐ No → *Go to Question N1.*

☐ Yes

M8. Are you currently pregnant?

☐ No

☐ Yes

Continue to Question M11 below.

Male

M9. Has a woman ever been pregnant by you?

☐ No → *Go to Question N1.*

☐ Yes

M10. Is she currently pregnant?

☐ No

☐ Yes

Continue to Question M11 below.

M11. 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	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

Please! Do not mark below this line

HEALTH BEHAVIORS

Alternative Medicine

N1. In this section, we would like to know about any alternative therapy or complementary healing techniques that you have used during the last year.
(Mark all that apply)

	No	Yes	Not sure
a. Acupuncture	☐	☐	☐
b. Biofeedback	☐	☐	☐
c. Chiropractor	☐	☐	☐
d. Crystals/magnets	☐	☐	☐
e. Nutritional supplements (such as Omega-3 fatty acids)	☐	☐	☐
f. Herbal remedies (such as St. John's Wort, Echinacea)	☐	☐	☐
g. Homeopathic remedies	☐	☐	☐
h. Hypnosis/guided imagery	☐	☐	☐
i. Massage/body work	☐	☐	☐
j. Meditation/relaxation	☐	☐	☐
k. Modified diet (gluten-free, vegan)	☐	☐	☐
l. Naturopathic treatments	☐	☐	☐
m. Spiritual healing/prayer	☐	☐	☐
n. Therapeutic touch	☐	☐	☐
o. Vitamins/minerals (not regular multi-vitamin, but high dose C, zinc, etc.)	☐	☐	☐
p. Yoga/Tai Chi/Qi Gong/special exercise	☐	☐	☐
q. Other	☐	☐	☐

If Other, please specify.

N2. Some people get a general physical examination from a doctor once in a while even though they are feeling well and have not been sick. When was the last time you had a general physical examination when you were not sick?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N3. When was the last time you had an echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N4. When was the last time you had a test to measure your bone strength or bone mineral density (such as a DEXA, quantitative CT scan, or ultrasound)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N5. How long has it been since you last went to a dentist?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N6. When was the last time you had an MRI of your heart (you were placed inside a scanner, like a long tube)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N7. When was the last time you had an MRI of your head or brain?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N8. When was the last time you had an ultrasound of the thyroid gland?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N9. When was the last time you had an ultrasound of the carotid arteries (blood vessels in the neck)?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N10. When was the last time you had a skin exam for cancer by a healthcare provider?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N11. When was the last time you had a home blood stool test to determine whether your stool contains blood?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N12. When was the last time you had a sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N13. During the past 12 months, have you had either a flu shot or a flu vaccine that was sprayed in your nose?

☐ Yes ☐ No ☐ Don't Know

N14. A pneumonia shot or pneumococcal vaccine is usually given only once or twice in a person's lifetime and is different from the flu shot. Have you ever had a pneumonia shot?

☐ Yes ☐ No ☐ Don't Know

N15a. Have you ever had zoster (shingles)?

☐ No → *Go to Question N16.*

☐ Yes

If yes, indicate number of times and date(s) of occurrence(s).

Times	Month	Year

Please use a separate sheet of paper for additional dates.

N15b. Since completing your cancer treatment, did you take chronic medications because of shingles?

☐ No ☐ Yes

N15c. Do you currently take chronic (for more than 1 month) medications because of shingles?

☐ No ☐ Yes

N16. Since completing your cancer treatment, have you ever been hospitalized for infection?

☐ No ☐ Yes

Note date(s) and sites(s) of infection:

Date of infection	Site of infection (lung, blood, sinus, brain, etc.)

Please use a separate sheet of paper for additional dates and sites.

Males → Go to Question N26 next page.

N17. FEMALES - How often do you perform monthly breast self-examinations?

☐ Regularly (once a month)

☐ Occasionally

☐ Rarely or never

N18. FEMALES - When was the last time you had a Pap smear (test for cancer of the cervix)?

☐ Never → *Go to Question N20.*

☐ Less than 1 year ago

☐ 1-2 years ago

☐ More than 2 years ago but less than 5 years ago

☐ 5 or more years ago

☐ I don't know if I ever had one

☐ I had one, but I don't recall when

N19. FEMALES - Have you ever required surgical treatment for an abnormal Pap smear (cone biopsy, laser surgery, loop electrosurgical excision (LEEP), removal of cervix, etc.)?

☐ No ☐ Yes

N20. FEMALES - When was the last time you had a breast examination by a doctor or a health care professional?

☐ Never

☐ Less than 1 year ago

☐ 1-2 years ago

☐ More than 2 years ago but less than 5 years ago

☐ 5 or more years ago

☐ I don't know if I ever had one

☐ I had one, but I don't recall when

N21. FEMALES - Have you ever had a mammogram?

☐ Yes ☐ No → *Go to Question N22.*

N21a. How old were you when you had your first mammogram? . . . .

N21b. When was the last time you had a mammogram?

☐ Never

☐ Less than 1 year ago

☐ 1-2 years ago

☐ More than 2 years ago but less than 5 years ago

☐ 5 or more years ago

☐ I don't know if I ever had one

☐ I had one, but I don't recall when

Please! Do not mark below this line

N22. FEMALES - When was the last time you had a breast ultrasound?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N23. FEMALES - When was the last time you had a breast MRI?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N24. FEMALES - The human papillomavirus (HPV) vaccine is given to prevent cervical cancer in girls and women. The HPV vaccine is sometimes called the HPV shot, Cervarix, or Gardasil. Have you ever received one or more doses of the HPV vaccine?

- ☐ Yes
- ☐ No → *Go to Question N25.*
- ☐ Don't Know → *Go to Question N25.*

N24a. How old were you when you received the first dose of the HPV vaccine? . . . . . ☐☐

N24b. How many shots of the HPV vaccine did you receive?

☐ 1 shot ☐ 2 shots ☐ 3 shots ☐ Don't Know

N25. FEMALES- A human papillomavirus (HPV) test is used to test for HPV infection. Have you ever had an HPV test?

- ☐ Yes
- ☐ No → *Go to Question O1, next page.*
- ☐ Don't Know → *Go to Question O1, next page.*

N25a. How long has it been since your last HPV test?

- ☐ Within the past year (less than 12 months ago)
- ☐ Within the past 3 years (more than 1 year but less than 3 years ago)
- ☐ Within the past 5 years (more than 3 years but less than 5 years ago)
- ☐ Don't Know

Females → Go to Question O1, next page.

N26. MALES - When was the last time you had a PSA or blood test to detect prostate cancer?

- ☐ Never
- ☐ Less than 1 year ago
- ☐ 1-2 years ago
- ☐ More than 2 years ago but less than 5 years ago
- ☐ 5 or more years ago
- ☐ I don't know if I ever had one
- ☐ I had one, but I don't recall when

N27. MALES- The human papillomavirus (HPV) vaccine is given to prevent HPV infection and genital warts in boys and men. The HPV vaccine is sometimes called the HPV shot, Cervarix, or Gardasil. Have you ever received one or more doses of the HPV vaccine?

- ☐ Yes
- ☐ No → *Go to Question O1, next page.*
- ☐ Don't Know → *Go to Question O1, next page.*

N27a. How old were you when you received the first dose of the HPV vaccine? . . . . . ☐☐

N27b. How many shots of the HPV vaccine did you receive?

☐ 1 shot ☐ 2 shots ☐ 3 shots ☐ Don't Know

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.

O1. Have you been admitted to a hospital in the last 12 months?

☐ No → *Go to Section P, next page.*

☐ Yes

O2. How many times have you been admitted to a hospital in the last 12 months? ☐☐

O3. What was the reason for the first hospitalization?

O3a. What procedures/surgeries were performed?

O3b. Where were you hospitalized?

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

O3c. Date of first hospitalization:

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

O3d. How many days were you hospitalized?

☐☐☐ **Days**

O4. What was the reason for the second hospitalization?

O4a. What procedures/surgeries were performed?

O4b. Where were you hospitalized?

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

O4c. Date of second hospitalization:

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

O4d. How many days were you hospitalized?

☐☐☐ **Days**

Please use a separate sheet of paper for additional hospitalizations

Please! Do not mark below this line

GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions. Indicate "Yes" only if a physician has told you that you were born with, or have the condition.

Because we need definite responses, and questions left blank are difficult to interpret, it is very important that you mark an answer for each of the following questions, even if you have never had that condition. If you have never heard of these conditions, it is unlikely that you have had them.

P1a. Have you <u>ever</u> 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. Polycystic kidney disease.	☐	☐	☐
q. WAGR syndrome.	☐	☐	☐
r. Li-Fraumeni syndrome (p53 gene abnormality).	☐	☐	☐
s. Any other genetic disorder	☐	☐	☐

If yes, describe this disorder.

P1b. Has anyone in your immediate family (blood relatives only) or your spouse <u>ever</u> had any of the conditions in question P1a? *(Mark all that apply)*

What conditions?

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

CONDITIONS PRESENT AT BIRTH

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.

P2. Have you <u>ever</u> had genetic counseling for cancer risk?

- ☐ No
- ☐ Yes

Continue on next page.

Please! Do not mark below this line

P3a. 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 defect, please specify.

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

If other, please specify.

P3b. Has anyone in your immediate family (blood relatives only) or your spouse <u>ever</u> had any of the conditions in Question P3a? *(Mark all that apply)*

What conditions?

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

P4. Has anyone in your immediate family (blood relatives only) or your spouse <u>ever</u> had cancer? *(Mark all that apply)*

What types?

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

Please! Do not mark below this line

CONTACT INFORMATION

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 you can recall, what was your home address <u>at the time you were treated for childhood cancer</u>?

Address	
City	State
Zip Code	

We have your current address and phone as:

Is this information correct, or are you planning on moving in the next 6 months?

☐ Correct ☐ Not correct ☐ Moving

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

☐ No ☐ Yes

Your Email Address

Please give us your correct address or location (if different from above):

Address		
City	State	
Zip Code	Home Phone Number	Cell Phone Number

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

Name	
Address	Relationship to you
City	State
Zip Code	Phone Number

Please! Do not mark below this line

For our future planning, what type of information or help do you think should be available to survivors of childhood cancer, leukemia, tumor, or similar illnesses?

Attach additional pages, if necessary.

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

Mail to:

SJLIFE 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