# Long-Term Follow-Up Study

# UNIVERSITY OF MINNESOTA

University of Minnesota The Denver Children's Hospital Children's Hospital of Pittsburgh Children's Hospital at Stanford Dana-Farber Cancer Institute Emory University Children's National Medical Center U.T.M.D. Anderson Cancer Center Memorial Sloan Kettering Cancer Center Texas Children's Hospital University of California at San Francisco Seattle Children's Hospital & Medical Center Toronto Hospital for Sick Children St. Jude Children's Research Hospital Children's Hospital of Columbus Roswell Park Cancer Institute Mayo Clinic Children's Health Care - Minneapolis Children's Hospital of Philadelphia St. Louis Children's Hospital Children's Hospital of Los Angeles UCLA Medical Center Miller Children's Hospital Children's Hospital of Orange County Riley Hospital for Children-Indiana University UAB/The Children's Hospital of Alabama University of Michigan-Mott Children's Hospital Children's Medical Center of Dallas

> Our mailing address is: Long-Term Follow-Up Study Department of Pediatrics University of Minnesota 420 Delaware St. SE Mayo Mail Code 715 Minneapolis, MN 55455

Toll-free phone number: 1-800-775-2167

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

It has been about two years since we sent you our last general survey and we would like to update some information. Please fill out the following form to bring us up-to-date on your health in the past two years.

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

Your generosity in participating is greatly appreciated.

Sincerely

The LTFU study staff

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

Self Pa	irent 🗌 Other:			
Today's date:		]/[		]

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

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



#### MARKING EXAMPLES

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

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	Not sure	If yes, age at first use
	exercise?	Yes	
2.	Have you ever taken		years
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	🛛	34
3.	When was this condition diagnosed? $ \begin{array}{c c} 0 & 4 \\ \hline 0 & 4 \\ \hline Month (mm) \\ \end{array} $ Year (yyyy)		

In the past we have asked you questions similar to those below. We would like to update this information.  1. What is the highest grade or level of schooling you have now completed?   1. What is the highest grade school)  1. How a power of the school is	<ul> <li>4. What is your current employment status? Include unpaid work in the family business or farm. (mark all that apply)</li> <li>Working full-time (30 or more hours per week)</li> <li>Working part-time (less than 30 hours per week)</li> <li>Caring for home or family (not seeking paid work)</li> <li>Unemployed and looking for work</li> <li>Unable to work due to illness or disability</li> <li>Retired</li> <li>Student</li> <li>Other - Specify:</li> </ul>
	If you are not currently working full or part time Go to Question 7.
<ul> <li>2. Which of the following best describes your current marital status?</li> <li>Single</li> <li>Married</li> <li>Living with a partner as married</li> <li>Widowed</li> <li>Divorced</li> <li>Separated or no longer living as married</li> </ul>	<ul> <li>5. 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:</li> <li>5a. Main job title:</li> <li>5b. Please briefly describe the primary tasks in your job:</li> </ul>
<ul> <li>3. What is your current living arrangement? (mark all that apply)</li> <li>Live with spouse/partner</li> <li>Live with parent(s)</li> <li>Live with roommate(s)</li> <li>Live with brother(s) and/or sister(s)</li> <li>Live with other relative(s)</li> <li>Live alone</li> <li>Other - Specify</li> </ul>	<ul> <li>6. When you are at work, which of the following best describes what you do? Would you say:</li> <li>Mostly sitting or standing</li> <li>Mostly walking</li> <li>Mostly heavy labor or physically demanding work</li> <li>7. What is your current height without shoes?</li> <li>Feet Inches</li> <li>8. What is your current weight without shoes?</li> </ul>
Pleasel Do not mark	Pounds

## A. MEDICAL CARE

# The next questions are about health care received during

A. MEDICAL CARE	6. Did you discuss any of the following issues with your
The next questions are about health care received during the 2 year period between:	physician or primary health care provider during any of these visits? <i>(mark all that apply)</i>
<ul> <li>1. During this two year period, which of the following health care providers (excluding dentists) did you see or talk to for medical care? This includes routine and sick care. (mark all that apply)</li> <li>None&gt; Go to Question 9.</li> <li>Physician (including osteopath)</li> <li>Nurse</li> <li>Chiropractor</li> <li>Physical therapist</li> <li>Other - Specify:</li> </ul>	<ul> <li>None</li> <li>Heart disease</li> <li>Osteoporosis (weak or brittle bones)</li> <li>Risk of developing cancer (breast, skin, other)</li> <li>Hepatitis C</li> <li>Dental problems</li> <li>Fertility issues (ability to get pregnant)</li> <li>Mental health</li> <li>Other cancer-related issues - please specify:</li> </ul>
<ol> <li>Where did you receive your health care?</li> </ol>	<ol> <li>If you had a routine check-up or one that you scheduled because of reading the LTFU newsletter</li> </ol>
<ul> <li>(mark all that apply)</li> <li>Doctor's office</li> <li>Oncology (cancer) center or clinic</li> <li>Other type of clinic</li> <li>Hospital</li> <li>Emergency room or urgent care center</li> <li>Long-term follow-up clinic</li> <li>Other - Specify:</li> </ul>	<ul> <li>do you feel that</li> <li>Your doctor was familiar with health problems that develop after childhood cancer and similar illnesses.</li> <li>Your doctor was NOT familiar with health problems that develop after childhood cancer and similar illnesses.</li> <li>Did not have a check-up. → Go to Question 9</li> </ul>
	<ul> <li>8. At that check-up did your doctor</li> <li>a. Give you advice about what to do to reduce risks</li> </ul>
<ul> <li>3. During this 2 year period, how many times did you see a physician?</li> <li>None 7-10 times</li> <li>1-2 times 11-20 times</li> <li>3-4 times More than 20 times</li> <li>5-6 times</li> <li>4. Why did you seek medical care? (mark all that apply) <ul> <li>Routine check-up</li> </ul> </li> </ul>	<ul> <li>b. Discuss or order medical screening tests</li> <li>c. Suggest you see a cancer specialist</li> <li>d. Suggest you see another type of medical subspecialist(s)</li> <li>e. Tell you that you had nothing to worry about based on findings at the check-up</li> <li>f. Other</li> <li>Specify:</li> </ul>
Specific problem(s) - please specify:	
	<ul> <li>9. Do you currently have a treatment summary or copies of your medical records of your childhood cancer or similar illness?</li> <li>No Yes Don't know</li> </ul>
<ul> <li>5. How many of these visits were related to your previous cancer or similar illness?</li> <li>None 7-10 times</li> <li>1-2 times 11-20 times</li> <li>3-4 times More than 20 times</li> <li>5-6 times</li> </ul>	<ul> <li>10. Does your local/primary care doctor have a summary of your treatment for childhood cancer or similar illness or copies of your medical records from your cancer treatment center?</li> <li>No Yes Don't know</li> <li>Don't have local primary care doctor</li> </ul>

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## **B. MEDICAL SCREENING TESTS**

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

When was the last time you had. . .

Never

1.	An echocardiogram (ultrasound of the heart to
	look at the heart muscle and heart valves)?

	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
2.	A colonoscopy (a procedure to view your entire colon)?
	Never
	Less than 1 year ago

1-2 years ago

More than 2 years but less than 5 years ago

5 or more years ago

Don't know

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

Never

Less than 1 year ago

🗌 1-2 years ago

More than 2 years but less than 5 years ago

5 or more years ago

Don't know

MALES Go to Question 6. FEMALES

When was the last time you had. . .

4. A mammogram?

Never
Less than 1 year ago
1-2 years ago

More than 2 years but less than 5 years ago

5 or more years ago

Don't know

5. A pap smear (test for cancer of the cervix)?

Never

Less than 1 year ago

1-2 years ago

More than 2 years but less than 5 years ago

5 or more years ago

Don't know

Not sure

6. Did you receive a blood transfusion (red cells, platelets, fresh frozen plasma) during your treatment for cancer or similar illness?

🗌 No		
☐ Yes →	How old were you?	

7. Have you received a blood transfusion for another reason either before your cancer or similar illness was diagnosed or since you finished treatment (blood transfusions are sometimes given after a lot of blood loss, such as with a car accident)?

No		
☐ Yes →	How old were you?	
Not sure		

8. Has a doctor or health care professional ever tested you for hepatitis C? (check only one)

No		
🗌 Yes	How old were you?	
Not sure		

9. If you answered "yes" to question 8, what was the result of the test? (*check only one*)

Positive for hepatitis C (means that you are or have been infected with hepatitis C)

Negative for hepatitis C (means that you have never been infected with hepatitis C)

Not sure

## SUN SENSITIVITY

<u>C.</u>	SUN SENSITIVITY	7. Have you ever sunbathed or sat outside by the water?
1.	How would you describe your natural skin color on parts of your body <u>not exposed to the sun?</u> Pale or milky white Very light brown, sometimes freckles Light tan, brown, or olive	<ul> <li>No&gt; Go to Question 9.</li> <li>Ves</li> <li>8. If yes, how many days in the last 12 months have you sunbathed or sat outside by the water?</li> </ul>
	Brown, dark brown, or black	None 6-10 days
2.	What color are your eyes?	1-5 days 11 or more days
	Blue-grey     Dark brown/black       Hazel     Mixed/other	<ul> <li>9. Have you ever used artificial tanning devices such as a sunlamp, or gone to a tanning booth?</li> </ul>
	Green	$\square \text{ No} \longrightarrow \text{Go to Question 11.}$
3.	What is your natural adult hair color? (check only one)	↓ Ves
	Light blond       Strawberry (reddish) blond         Blond       Red         Light brown       Dark brown/black	10. If yes, how many days in the last 12 months have you used any artificial tanning devices such as a sun lamp, or gone to a tanning booth?
	Medium brown     Jet black	None 6-10 days
	Red-brown	1-5 days 11 or more days
ho	Inburn is a reddening of the skin that lasts at least 12 Furs after you have been outdoors in the sun. Suppose that after several months of not being in the	11. When you were outside last summer for more than 15 minutes how often did
т.	sun, you went out in the sun without a hat, sunscreen, or protective clothing for an hour. Would you (check only one)	15 minutes, how often did you protect yourself from the sun by Rarely
	<ul> <li>Never tan, always burn</li> <li>Sometimes tan, usually burn</li> <li>Usually tan, sometimes burn</li> <li>Always tan, rarely burn</li> </ul>	Applying a sunscreen with a sun protection factor (SPF) of 15 or more on all sun exposed skin areas
5.	Thinking back when you were a child/adolescent (less than 21 years old), how often have you had a severe, painful sunburn on each of these areas of the body?       3-5 times         Back and shoulders       I-2 times         Never       I         Back and shoulders       I         Face or arms       I         All over       I	Wearing protective clothing such as long-sleeved shirts and long pants       Image: Image
lf y	you are under 21:> Go to Question 7.	or most of your skin for signs of skin cancer, not
6.	As an adult (age 21 or older), how often have you had a severe, painful sunburn on each of these areas of the body?	just looked at a certain spot?
	Back and shoulders       Image: I	<ul><li>13. Have you ever had a health care professional remove a skin growth?</li><li>No Yes</li></ul>

<ul> <li>14. Have you ever been told that yo This includes basal cell, squame melanoma.</li> <li>No&gt; Go to Section</li> </ul>	ous cell, and	v Ia
		k
$\checkmark$ _		2.
What was the name of the disease	)	
Where was the skin cancer located	on your body	?
When was this diagnosed?		3.
Month (		
(	nm) Year (	уууу)
If you don't remember the date whe	n the skin can	icer
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha	n the skin can proximate age	icer
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha	n the skin can proximate age	icer e at
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983).	n the skin can proximate age	icer e at
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983). Where was this diagnosed?	n the skin can proximate age	icer e at
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name	n the skin can proximate age	e at 4.
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name	n the skin can proximate age	e at 4.
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name	n the skin can proximate age	e at 4.
If you don't remember the date whe was diagnosed, please give your ap the time, or a time period when it ha <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name Hospital or clinic	n the skin can proximate age	e at 4.

If you had more than one occurrence of skin cancer, please use a separate sheet of paper.

#### **D. PHYSICAL ACTIVITY**

The rest of the questions on this page are about exercise, recreation, or physical activities other than your regular job duties.

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

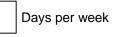
We are interested in two types of physical activity: vigorous and moderate. Vigorous activities cause large increases in breathing or heart rate while moderate activities cause small increases in breathing or heart rate.

2. Now thinking about the <u>vigorous physical activities</u> 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?





3. How many days per week do you do these <u>vigorous</u> <u>activities</u> for at least 10 minutes at a time?



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

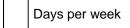


Minutes per day

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



6. How many days per week do you do these <u>moderate</u> <u>activities</u> for at least 10 minutes at a time?



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



Minutes per day

7



The questions on the next four pages are about your general health, well-being, and quality of life. These pages also include questions about the effects of your experience with cancer or a similar illness. Even if you do not think that your illness affects your life it is important for us to know that, too. So please answer all the questions to the best of your ability.

#### E. DAILY ACTIVITIES

This section is about your health and daily activities during the <u>PAST 4 WEEKS</u>. Please try to answer every question as accurately as you can.

1. In general, would you say your health is . . . *(mark one)* 

Excellent	🗌 Fair
Very good	Poor
Good	

- 2. <u>Compared to one year ago</u>, how would you rate your health in general now? *(mark one)* 
  - Much better now than one year ago
  - Somewhat better now than one year ago
  - About the same
  - Somewhat worse now than one year ago
  - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your physical health now limit you in these No, not limited at all activities? If so, how much? (check one response on Yes, limited a little each line) Yes, limited a lot 3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports-----4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf------5. Lifting or carrying groceries------6. Climbing several flights of stairs------7. Climbing one flight of stairs-----8. Bending, kneeling, or stooping-----9. Walking more than a mile-----10. Walking several blocks------11. Walking one block-----12. Bathing or dressing yourself------

During the <u>past 4 weeks</u>, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? *(mark one response on each line)* 

•		
13. Cut down the <b>amount of time</b> you spend on work or other activities	No	Yes
14. Accomplished less than you would like-		
15. Were limited in the <b>kind</b> of work or other activities		
16. Had <b>difficulty</b> performing the work or other activities (for example, it took extra effort)		
During the <u>past 4 weeks</u> , have you had any o following problems with your work or other re- activities <b>as a result of any emotional probl</b> (such as feeling depressed or anxious)? (ch response on each line)	gular I <b>ems</b> eck d	one
17. Cut down the <b>amount of time</b> you	No	Yes
spend on work or other activities		
18. Accomplished less than you would like-		
19. Didn't do work or other activities as carefully as usual		
20. During the <u>past 4 weeks</u> , to what extent h physical health or emotional problems with your normal social activities with fam neighbors, or groups? (mark one)	inter	fered
Not at all Quite a bit		
Slightly Extremely		
Moderately		
21. How much body pain have you had durin past 4 weeks? (mark one)	g the	
None Moderate		
Very mild Severe		
Mild Very severe		
22. During the <u>past 4 weeks</u> , how much did b pain interfere with your normal work (inclu- both work outside the home and housewe (mark one)	uding	
Not at all Quite a bit		
A little bit Extremely		
Moderately		

# F. HEALTH AND WELL-BEING

These questions are about how you feel and how things have been with you during the <u>PAST 4 WEEKS</u>. For each question, please mark the one answer that comes closest to the way you have been feeling. (mark one response

on each line) None of the time					
	A little of the time				
	Some of the time				
	A good bit of the time				
How much of the time	Most of the time				
<u>during the past</u> <u>4 weeks</u>	All of the time				
<ol> <li>Did you feel full of pep</li> <li>Have you been a very</li> </ol>					
person?					
3. Have you felt so down dumps that nothing co					
you up?					
4. Have you felt calm and peaceful?					
5. Did you have a lot of	8				
energy?					
<ol> <li>Have you felt downhea and blue?</li> </ol>					
7. Did you feel worn out?					
8. Have you been a happ	y 1				
<ul><li>9. Did you feel tired?</li></ul>					
-					
	<u>(s</u> , how much of the time has or <b>emotional problems</b> 1				
interfered with your so	cial activities (like visiting 1				
friends, relatives, etc.)	? (mark one) 1				
All of the time	A little of the time				
Most of the time	None of the time 1				
Some of the time	1 Definitely false				
How true or false is each	Mostly false				
of the following	Don't know				
statements for you? (check one response	Mostly true				
on each line)	Definitely true 2				
11. I seem to get sick a litt					
than other people					
12. I am as healthy as any	body I know 🔄 📄 📄 🔲				
13. I expect my health to g	et worse				
14. My health is excellent-					

### **G. FEELINGS/EMOTIONS**

The next set of questions 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

	tressed or bothered			Extremely
	<u>u during the past</u> lays including today.		G	Quite a bit
	rk only one answer		Moder	ately
for	each problem and			
do	not skip any items.	Δ	little bit	
		Not a	t all	
1.	Nervousness or shaking			
2.	Faintness or dizziness			
3.	Pains in heart or chest			
4.	Thoughts of ending your	life		
5.	Suddenly scared for no r			
6.	Feeling lonely			
7.	Feeling blue			
8.	Feeling no interest in thir	ngs		
9.	Feeling fearful			
10.	Nausea or upset stomac	h		
	Trouble getting your brea			
12.	Numbness or tingling in your body			
13.	Feeling hopeless about t	he future		
14.	Feeling weak in parts of	your body-		
15.	Feeling tense or keyed u	ıp		
16.	Spells of terror or panic-			
17.	Feeling so restless you ostill			
18.	Feelings of worthlessnes	s		
19.	Do you currently have pa cancer or similar illness,			our
	🗌 No pain	Alc	ot of pai	n
	Small amount of pair		y bad,	
	Medium amount of pa	ain exc	ruciatin	ig pain
20.	Do you currently have ar your cancer or similar illr			
	No anxiety/fears			
	Small amount of anxi	ety/fears		
	Medium amount of ar	nxiety/fears		
	A lot of anxiety/fears			
	Very many, extreme	anxiety/fea	ſS	



## H. PERSONAL GROWTH

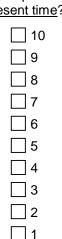
# For each of the statements below, indicate how much you are influenced by your childhood cancer or similar illness, using the following scale:

			Very g	great	influe	nce				
I am NOT influenced by my illness.		Great influence								
I am influenced to a VERY SMALL degree as a result of my illness. I am influenced to a SMALL degree as a result of my illness.	Мос	derate	influe	nce						
I am influenced to a MODERATE degree as a result of my illness. I am influenced to a GREAT degree as a result of my illness.	Smal	l influe	ence							
I am influenced to a VERY GREAT degree as a result of my illness.	Very small influ	ence								
	No influence									
1. My priorities about what is important in life										
2. I'm more likely to try to change things which need changing										
3. An appreciation for the value of my own life										
4. A feeling of self-reliance										
5. A better understanding of spiritual matters										
6. Knowing that I can count on people in times of trouble										
7. A sense of closeness with others	🗌									
8. Knowing I can handle difficulties										
9. A willingness to express my emotions										
10. Being able to accept the way things worked out										
11. Appreciating each day	🗌									
12. Having compassion for others	🗌									
13. I'm able to do better things with my life										
14. New opportunities are available that wouldn't have been otherwise										
15. Putting effort into my relationships										
16. I have a stronger religious faith										
17. I discovered that I'm stronger than I thought I was										
18. I learned a great deal about how wonderful people are										
19. I developed new interests	[]									
20. I accept needing others										
21. I established a new path for my life	🗌									

# I. LADDER OF LIFE

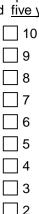
#### Here is a ladder representing the "Ladder of Life." The top of the ladder represents the best possible life for you. The bottom of the ladder represents the worst possible life for you. (Answer questions 1 through 3.)

 On which step of the ladder do you feel you personally stand at the present time?



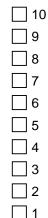
Best Possible Life
10
9
8
7
6
5
4
3
2
1
Worst Possible Life

On which step would you have stood <u>five years ago</u>?



3. Thinking about your future, on which step do you think you will stand about <u>five years from now</u>?

1



J. PROBLEM SOLVING
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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 <u>the past 6 months</u>. Please complete all items. Please think about yourself as you read these statements and mark one response on each line:

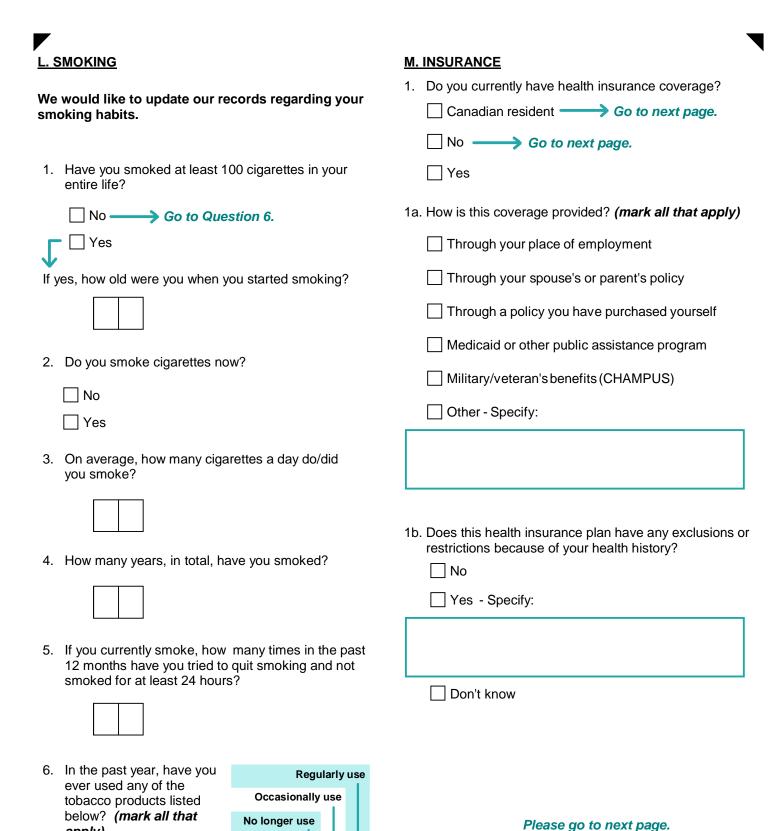
		Often a proble				
	s	Sometimes a	lem			
		Never a prob	lem			
1.	I get upset easily					
2.	It takes me longer to complete	my work				
3.	I don't think of consequences b acting					
4.	I am disorganized					
5.	I forget instructions easily				Ш	
6.	I have problems completing my	work				
7.	I have difficulty recalling things previously learned (e.g., names events, activities)	s, places				
8.	I get frustrated easily					
9.	My mood changes frequently					
	I have difficulty coming up with ways of solving a problem					
	I am impulsive					
12.	I have trouble finding things in r bedroom, closet or desk	ny 				
13.	I forget what I am doing in the r things	niddle of			П	
14.	I have problems getting started	on my				
15.	I am an underachiever					
16.	I am easily overwhelmed					
17.	I have trouble doing more than at a time	one thing				
18.	I blurt things out					
	. My desk/workspace is a mess					
20.	I have trouble remembering thir for a few minutes (such as direc phone numbers, etc.)	ctions,				
21	I have trouble prioritizing my ac					
	I read slowly				H	
	I am slower than others when c	ompleting				
24	my work				Ш	
<u> </u>	my head					
25.	I don't work well under pressure	ə				

## K. FEELINGS ABOUT PREVIOUS ILLNESS

Below is a list of problems that people sometimes have after experiencing cancer or				Almost always							
	lar illness in childhood or adolescence. Read each one carefully and mark the nat best describes how often that problem has bothered you in <u>the past month</u> .	F	lalf t	he ti	me						
	each problem with respect to your childhood illness.	Once in	a wł	nile							
		Not at all									
1.	Having upsetting thoughts or images about your illness that came into your head when you	only one ti	me I								
	didn't want them										
2.	Having bad dreams or nightmares about your illness										
3.	Reliving your illness, acting or feeling as if it was happening										
4.	Feeling emotionally upset when you were reminded of your illness (for example, feeling sca angry, sad, guilty, etc.)										
5.	Experiencing physical reactions when you were reminded of your illness (for example, brea out in a sweat, heart beating fast)	aking									
6.	Trying not to think about, talk about, or have feelings about your illness										
7.	Trying to avoid activities, people, or places that remind you of your illness										
8.	Not being able to remember an important part of your experience with your illness										
	Having much less interest or participating much less often in important activities										
10.	Feeling distant or cut off from people around you										
11.	Feeling emotionally numb (for example, being unable to cry or unable to have loving feeling	gs)									
12.	Feeling as if your future plans or hopes will not come true (for example, you will not have a career, marriage, children, or a long life)										
13.	. Having trouble falling or staying asleep										
14.	Feeling irritable or having fits of anger										
	Having trouble concentrating (for example, drifting in and out of conversations, losing track story on television, forgetting what you read)										
16.	Being overly alert (for example, checking to see who is around you, being uncomfortable w your back to a door, etc.)	/ith 									
17.	Being jumpy or easily startled (for example, when someone walks up behind you)										

Please go to next page.





Please! Do not mark below this line

Never used

Chewing tobacco-----

apply)



#### FAMILY HISTORY INFORMATION

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

#### Cancer

#### Any diagnosis of cancer or malignant tumor, such as:

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

#### **Conditions Present at Birth**

#### Any abnormality present at birth, such as:

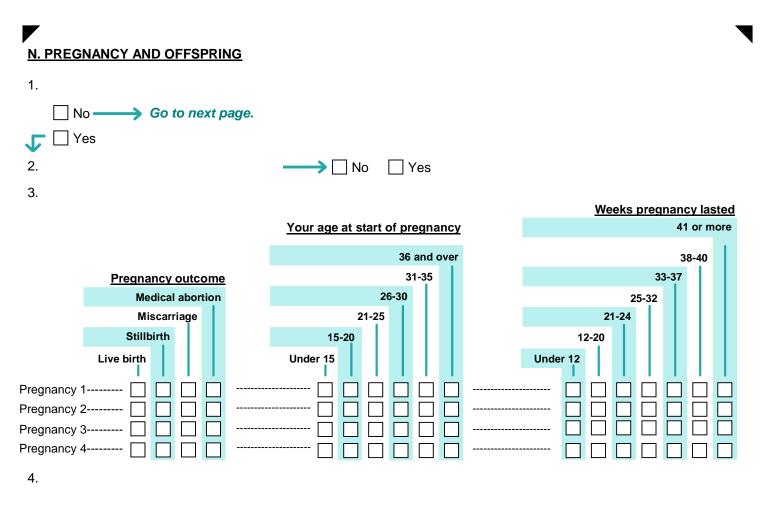
Blindness or difficulty seeing Crossed eyes (strabismus) Eyes different colors Hare lip (cleft lip) Hole in roof of mouth (cleft palate) Absent, fused or extra fingers or toes Hip displacement Diverted urinary stream (hypospadias) Undescended testicle (cryptorchism) Deafness or imparied hearing Shortened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

#### **Hereditary Conditions**

#### Some of the more common conditions known to be hereditary:

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





Indicate whether each child has a history of cancer, a birth defect, and/or any hereditary conditions (refer to the list of conditions on page 14). Please list twin births or multiple births as separate children. Use a separate piece of paper *if you need to record more pregnancies.* 

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

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

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



The	DENTAL HEA	n this p							No Ye	ot sur s	e	lf yes, age when first occurred	receiv for thi	e you ed care s in the years?
	alth and any d		are you may h	ave receiv	ved.			Ν	No				Yes	No
Hav	ve you ever .												<u> </u>	
1.			sing teeth bec	-		•		l		L				
2.			eased amount					[						
3.	Had abnorma	al shape	d (small or ma	alformed) te	eth?			[						
4.	Had abnorma	al root de	evelopment?					[						
5.	Had difficulty artificial saliv	in produ a?	ucing saliva (d	ry mouth) t	hat required t	treatme	ent such as	s [						
6.	Had severe g	gingivitis	or gum diseas	se requirinç	g surgery or d	leep cl	eaning?	[						
7.	Had root can	al therap	oy?					[						
8.	Had more that	an 5 cav	ities?					[						
9.	Lost 6 or mo	re teeth	due to decay o	or gum dise	ease?			[						
10	. Worn a denta	al bridge	(for missing o	or removed	teeth)?			[						
11	. Worn remova	able den	tures (comple	te or partia	l upper or low	ver or b	ooth)?	[						
12	. Worn a prost	thesis to	lift your palate	e to improv	e the quality c	of your	voice?	[						
13	. Had other de	ental trea	tment or surge	əry?				[						
	Type of procedure:													
14	. Had any othe	er dental	problems?					[						
	<i>If yes</i> , specify:							٦.						
		(Please	list any other	dental proc	edures on an	extra p	oage)							
15	. Have you eve	er had d	ental braces?			18.						eaned by the		n
	No	] Yes	Don't kno	W				_		gien		vithin the pas	st year	ſ
16	. Do you curre	ntly have	e dental insura	ince?			∐ No		Yes			Don't know		
	No	] Yes	Don't kno	wo		19.		al car				ng a dentist f your previc		
17	. Have you vis the past year			ntal clinic v	within		No	_	Yes			Don't know		
	No	Yes	🗌 Don't kn	ow										
•				Ple	ase! Do not mar	rk belov	v this line —							

## P. BONE HEALTH

P. BONE HEALTH							
The questions on this page are about problems that can occur with bone health.		Not	sure				
Osteoporosis is a condition in which bones become weak and can sometimes fracture too easily.	No	Yes		lf yes, age when first	Currently receiving care	No longer a	Still a
1. Have you ever been told by a physician or other health care professional that you had osteoporosis or osteopenia (thin, brittle or fragile bones)				occurred	for this?	problem	problem
2. Have you ever taken medications for osteoporosis or osteopenia?							
If no Go to Question 4.				Currently taking			
3. Which of the following medicines have you taken for this condition?				this?			
(a) Calcium or vitamin D (rocaltrol)							
(b) Estrogen or testosterone							
(c) Growth hormone	Ш						
<ul> <li>(d) Bisphosphonate drugs like alendronate, fosamax, actol, risdronate, or pamidronate</li> </ul>							
(e) Sodium fluoride							
(f) Calcitonin (calcimar, miacalcin)							
(g) Other Specify:							
Avascular necrosis (AVN) is a condition in which			sure		Currently		
blood supply to the bone joints becomes interrupted, causing that part of the bone to die.	No	Yes		lf yes, age when first occurred	receiving care for this?	No longer a problem	Still a problem
<ul> <li>4. Have you ever been told that you have avascular necrosis (also known as osteonecrosis)?</li> <li>If no Go to next page.</li> </ul>							
5. Have you ever received treatments for avascular necrosis? If no				Currently receiving			
6. Which of the following treatments have you received for AVN?				this?			
(a) Medications							
(b) Physical therapy							
(c) Joint injection							
(d) Surgery							
(e) Other							

Please! Do not mark below this line

Specify:

## Q. MEDICATIONS

Please indicate all medicines/drugs you took regularly during the two-year period between

Not sure If yes, age We are only asking about medicines/drugs which you took consistently at first use for more than one month, or for 30 days or more in a year. Please list Yes only drugs prescribed by a doctor and filled by a pharmacist. Include No pills, syrups, injections, patches, or creams. Please do NOT include medicine/drugs that you buy off the shelf at the drugstore vears 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, Epatch, Premarin, Provera, Medroxyprogesterone------If yes, specify the name of the drug(s) or indicate you do not know the specific name 3. TESTOSTERONES (MALE HORMONES) such as Delatesteral, Testosterone cypionate, Testosterone enanthate, Testoderm------If yes, specify the name of the drug(s) or indicate you do not know the specific name 4. PILLS FOR DIABETES, such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Orinase (tolbutamide), or Diabinese (chlorpropramide)------If yes, specify the name of the drug(s) or indicate you do not know the specific name INSULIN INJECTIONS FOR DIABETES such as insulin, Humulin, Novolin-------If yes, specify the name of the drug(s) or indicate you do not know the specific name 6. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION, such as Dyazide, Lotensin, Prinivil or Zestril (lisinopril), Normodyne (labetalol), Diovan-----If yes, specify the name of the drug(s) or indicate you do not know the specific name 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 8. 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 9. 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.

# R. CANCER, LEUKEMIA, OR TUMOR

 Since you last provided us information in have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse)? (You do not need to include skin cancers described on page 7.)

🗌 No —	$\rightarrow$	Go to next page.
↓ Ves		

What was the name of this disease?

Where was this diagnosed?

2. If you have had more than one additional cancer, leukemia, or tumor, since please describe below.

What was the name of this disease?

Where was this diagnosed?

Doctor's name

Hospital or clinic

Address

City, State, Zipcode

Was this a:

Doctor's name

Hospital or clinic

City, State, Zipcode

Address

Recurrence of original diagnosis

New cancer, leukemia, tumor, or similar illness

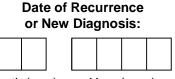
Don't know

Was this a:

Recurrence of original diagnosis

New cancer, leukemia, tumor, or similar illness

Don't know



Month (mm) Ye

Year (yyyy)

# Date of Recurrence or New Diagnosis:



Month (mm) Year (yyyy)





<u>s.</u>	INCOME	4.	If yes, what resources did you use to find out more
1.	Over the last year, what was the total income of the <u>household</u> you live in?	information about health problems after childhood cancer or similar illness? <i>(mark all that apply)</i>	
	Less than \$19,999 \$80,000 - \$99,999		Called the LTFU study toll-free line (1-800-775-2167)
	Section 20,000 - \$39,999 Over \$100,000		Called my local/primary care doctor
	S40,000 - \$59,999 Don't know		Had a check-up with my local/primary care doctor
	\$60,000 - \$79,999		Called my cancer doctor or center Had a check-up at my cancer center
			Used the Internet: <i>Which websites?</i>
2.	During the past year, how many people in this household were supported on this income?	Г	
	1 6		
			Other - Specify:
	3 8		
	4 9 or more		
	5		
3.		5.	What specific health problems featured in the newsletter were of interest to you? (mark all that apply)
	None \$40,000 - \$59,999		Second cancers Hepatitis C
	Less than \$19,999		Osteoporosis
	<b>\$20,000 - \$39,999 \$80,000 - \$99,999</b>		Heart disease
	Over \$100,000		Mental health
	LTFU NEWSLETTER	6.	If you spoke with a doctor or other health care professional, did you share a copy of the newsletter with your doctor at the check-up?
١.	In the past 2 years, did you read a newsletter from the LTFU Study?		No Yes Did not speak with doctor
	No Go to next page.		e would like to know how well our wsletter is keeping you informed
	Yes	ab	out health problems that may True
2.	Did any of the information reported in the		evelop after cancer or similar False
	newsletter make you feel anxious about your chances of developing health problems related to	Ple	ease answer the following questions:
	your treatment for cancer or a similar illness?	7.	Radiation treatment to the chest or
	Not at all anxious	0	spine is a risk factor for heart disease
	A little anxious	8.	Chest radiation treatment does not increase your risk of breast cancer
	Somewhat anxious	9.	Performing monthly breast exams is recommended since it may detect
З	Did the newsletter make you seek more information		tumors early, which may require less
0.	about health problems after treatment for childhood	10	treatment
	cancer or similar illness?	10	prednisone increases your risk for
	No> Go to question 5.	11	osteoporosis
	Yes		decrease your risk of osteoporosis

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

## LONG-TERM FOLLOW-UP STUDY Authorization for Release of Medical Information

I hereby authorize the release of all my hospital and physician records to Dr. Leslie Robison, Department of Pediatrics, Division of Epidemiology and Clinical Research, University of Minnesota.

I understand that all information obtained will be held strictly confidential and will be used for statistical purposes only.

This authorization will be effective for five years from the date of signature and may be canceled by me in writing at any time. A photocopy of this authorization will be treated in the same manner as the original.

Print your name

Signature

Date

Birthdate

This page is intentionally blank

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

Corr	ect
------	-----

Not correct

Moving

#### Please give us your correct address or location:

Address	
City	State
Zip Code	Phone Number

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

Name	
	Relationship to you
City	State
Zip Code	Phone Number

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

🗌 No	Yes —	Your Email Address			
On average, how many times per week do you use the internet?					
Never	1-10 times	10 or more times			
Please! Do not mark below this line					

23

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

Mail to:

LONG-TERM FOLLOW-UP STUDY MAYO MAIL CODE 715 420 DELAWARE ST SE MINNEAPOLIS MN 55455-9940

## Thank you!