# LIFU

#### Long-Term Follow-Up Study

#### SIBLING SURVEY

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

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FDIT

## UNIVERSITY OF MINNESOTA

Thank you for participating in the Long-Term Follow-Up Study. As the brother or sister of an individual who had childhood cancer or a similar illness, your participation continues to provide us with valuable information in the fight against these diseases.

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. Many of the questions in this survey concern experiences related to your brother's or sister's childhood illness. Even though you did not have cancer or a similar illness as a child, please respond to all the questions on the survey. Your responses will serve as a basis of comparison as we evaluate the responses of our participants who did have a childhood illness.

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:

lip:							
Parent	Other:						
	/	]/					
MM	DD	J	Y	Y	Y	Y	
		Parent Other:	Parent Other:	Parent  Other:	Parent  Other:	Parent Other:	Parent Other:

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 exercise?	Not sure Yes No	If yes, age at first use
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? 0       4       1       9       9       5         Month (mm)       Year (yyyy)		
	Please! Do not mark below this line		

8230002319

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 the 2 year period between:

- 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) Physician (including osteopath) 5. Did you discuss any of the following issues with your Nurse physician or primary health care provider during any Chiropractor of these visits? (mark all that apply) Physical therapist None Other - Specify: Heart disease Osteoporosis (weak or brittle bones) Risk of developing cancer (breast, skin, other) Hepatitis C Dental problems Fertility issues (ability to get pregnant) 2. Where did you receive your health care? Mental health (mark all that apply) Other cancer-related issues - please specify: 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: Please go to next page.
- 3. During this 2 year period, how many times did you see a physician?

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

5-6 times

Routine check-up

Specific problem(s) - please specify:



## **B. MEDICAL SCREENING TESTS**

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

When was the last time you had. . .

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

Never

- 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
- 6. Have you received a blood transfusion? (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		

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

No No		
☐ Yes →	How old were you?	
Not sure		

- 8. If you answered "yes" to question 7, 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

Please go to next page.

## 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	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 you had skin cancer? This includes basal cell, squamous cell, and melanoma.</li> <li>No&gt; Go to Section D Question 1, below.</li> </ul>	V V Ia M
r 🗌 Yes	b
What was the name of the disease?	2.
Where was the skin cancer located on your body?	
	J
When was this diagnosed?	3.
Month (mm) Year (yyyy)	
If you don't remember the date when the skin cancer	
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i>	4.
was diagnosed, please give your approximate age at	4.
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i>	4.
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983).	4.
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i>	
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983). Where was this diagnosed?	
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983). Where was this diagnosed?	
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name Hospital or clinic	
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was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name Hospital or clinic	4. 5.
was diagnosed, please give your approximate age at the time, or a time period when it happened ( <i>for</i> <i>example</i> , between 1980 and 1983). Where was this diagnosed? Doctor's name Hospital or clinic Address	

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

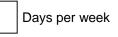
We are interested in two types of physical activity: vigorous and moderate. Vigorous activities cause large increases in breathing or heart rate while moderate activities cause small increases in breathing or heart rate.

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?

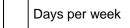


Minutes per day

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. 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

Good	

Very good Poor

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

No, not limited at all
Yes, limited a little
Yes, limited a lot
running, ting in
moving a ner, bowling,
🗆 🗆 🗖
airs
🗆 🗆
g 🗌 🗌 🗍
🔲 🗌
□ □ □
🗆 🗆 🗆

following problems v	<u>eeks</u> , have you had any c vith your work or other re t <b>of your physical healt</b> l <b>ach line)</b>	gular	
13. Cut down the an	nount of time you	No	Yes
	or other activities		
•	less than you would like-		
activities 16. Had <b>difficulty</b> p other activities (f	erforming the work or or example, it took		
following problems v activities <b>as a result</b>	eeks, have you had any c vith your work or other re t <b>of any emotional prob</b> ressed or anxious)? <i>(ch</i>	gular <b>lems</b>	one
17. Cut down the <b>an</b>			Yes
	or other activities		
•	less than you would like	-	
19. Didn't do work o <b>carefully</b> as usu	r other activities as Jal		
physical health with your norma	<u>4 weeks</u> , to what extent I or <b>emotional problems</b> I social activities with fam oups? <i>(mark one)</i>	s inter	fered
Not at all	Quite a bit		
Slightly	Extremely		
Moderately			
21. How much body past 4 weeks?	r pain have you had durin ( <b>mark one)</b>	g the	
None None	Moderate		
Very mild	Severe		
Mild	Very severe		
pain interfere wi	<u>4 weeks</u> , how much did l th your normal work (incl le the home and housew	uding	
Not at all	Quite a bit		
A little bit	Extremely		

Please! Do not mark below this line

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				
during the past 4 weeks	All of the time				
<ol> <li>Did you feel full of pep</li> </ol>					
2. Have you been a very	nervous				
<ul><li>person?</li><li>3. Have you felt so down</li></ul>					
dumps that nothing co you up?	uld cheer				
4. Have you felt calm and					
<ul><li>peaceful?</li><li>5. Did you have a lot of</li></ul>					
energy?					
<ol> <li>Have you felt downheat and blue?</li> </ol>					
7. Did you feel worn out?					
8. Have you been a happ person?					
<ol> <li>Did you feel tired?</li> </ol>					
your physical health of	<u>ks</u> , how much of the time has or <b>emotional problems</b> cial activities (like visiting ? <i>(mark one)</i>				
All of the time	A little of the time				
Most of the time	None of the time				
Some of the time					
	Definitely false Mostly false				
How true or false is each of the following	Don't know				
statements for you? (check one response	Mostly true				
on each line)					
11. I seem to get sick a litt than other people	Definitely true       le easier       In the second s				
12. I am as healthy as any	body I know 🔲 🗌 🔲 🔲 🔲				
13. I expect my health to g	jet 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			Extre	mely
	<u>u during the past</u> ays including today.		Q	uite a bit	2
	rk only one answer		Medara		
	each problem and		Modera	itery	
do	not skip any items.	Α	little bit		
		Not at	all		
1.	Nervousness or shaking	hands			
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			
11.	Trouble getting your brea	ath			
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	<mark> </mark>			
17.	Feeling so restless you o	ouldn't sit			
18.	Feelings of worthlessnes	S			
19.	Do you currently have pa	ain?			
	🗌 No pain		t of pair	۱	
	Small amount of pair	n 🗌 Ver	y bad, e	excrucia	ting
	Medium amount of pa	ain pair	1		
20.	Do you currently have ar your brother's/sister's illn				
	<ul> <li>No anxiety/fears</li> <li>Small amount of anxi</li> <li>Medium amount of ar</li> <li>A lot of anxiety/fears</li> <li>Very many, extreme a</li> </ul>	nxiety/fears	q		
		anviera/redi	3		



#### H. PERSONAL GROWTH

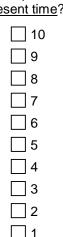
# For each of the statements below, indicate how much you are influenced by having a brother or sister who had childhood cancer or a similar illness, using the following scale:

I am NOT influenced by my brother's/sister's illness.		Very ç	great influ	Jence
I am influenced to a VERY SMALL degree as a result of my brother's/sister's illness.		Great	influence	2
I am influenced to a SMALL degree as a result of my brother's/sister's illness.		erate influe	nce	
I am influenced to a MODERATE degree as a result of my brother's/sister's illness.		influence		
I am influenced to a GREAT degree as a result of my brother's/sister's illness. I am influenced to a VERY GREAT degree as a result of my brother's/sister's	Very small influe	nce		
illness.	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

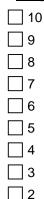
#### Here is a ladder representing the "Ladder of Life." The top of the ladder represents the best possible life for you. The bottom of the ladder represents the worst possible life for you. (Answer questions 1 through 3.)

 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

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 problen			lem
		Sometimes a problem			
		Never a prob	lem		
1.	I get upset easily				
2.	It takes me longer to complete	my work			
3. 4. 5. 6.	I don't think of consequences b acting I am disorganized I forget instructions easily I have problems completing m				
о. 7.	I have difficulty recalling things previously learned (e.g., name events, activities)	s I had s, places			
8. 9.	I get frustrated easily My mood changes frequently				
	I have difficulty coming up with ways of solving a problem	different			
	I am impulsive I have trouble finding things in bedroom, closet or desk	my			
	I forget what I am doing in the things	middle of			
14.	I have problems getting started own	d on my 			
	I am an underachiever				
	I am easily overwhelmed I have trouble doing more than				ш
	at a time				
	I blurt things out My desk/workspace is a mess-				님
	I have trouble remembering th for a few minutes (such as dire phone numbers, etc.)	ings, even ections,			
	I have trouble prioritizing my ad	ctivities			
	I read slowly I am slower than others when a my work	completing			
24.	I have trouble solving math pro my head	blems in			
25.	I don't work well under pressur				

## K. FEELINGS ABOUT ILLNESS

Below is a list of problems that people sometimes experience when they have a				nost	alwa	ays
	brother or sister who had a serious childhood illness. Read each one carefully and mark the box that best describes how often that problem has bothered you in <u>the</u>		Half the time		me	
<u>past m</u>	nonth. Rate each problem with respect to having a brother or sister with	Once in	a wł	nile		
cance	r or a similar illness.	Not at al only one ti				
1.	Having upsetting thoughts or images about your brother's or sister's illness that came into head when you didn't want them	vour				
2.	Having bad dreams or nightmares about your brother's or sister's illness					
3.	Reliving your brother's or sister's illness, acting or feeling as if it was happening					
4.	Feeling emotionally upset when you were reminded of your brother's or sister's illness (for feeling scared, angry, sad, guilty, etc.)					
5.	Experiencing physical reactions when you were reminded of your brother's or sister's illnes example, breaking out in a sweat, heart beating fast)					
6.	Trying not to think about, talk about, or have feelings about your brother's or sister's illness					
7.	Trying to avoid activities, people, or places that remind you of your brother's or sister's illne	əss				
8.	Not being able to remember an important part of your experience with your brother's or sis illness	ter's				
	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 feelin	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)	l 				
13.	Having trouble falling or staying asleep					
14.	Feeling irritable or having fits of anger					
15.	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.)					
17.	Being jumpy or easily startled (for example, when someone walks up behind you)					

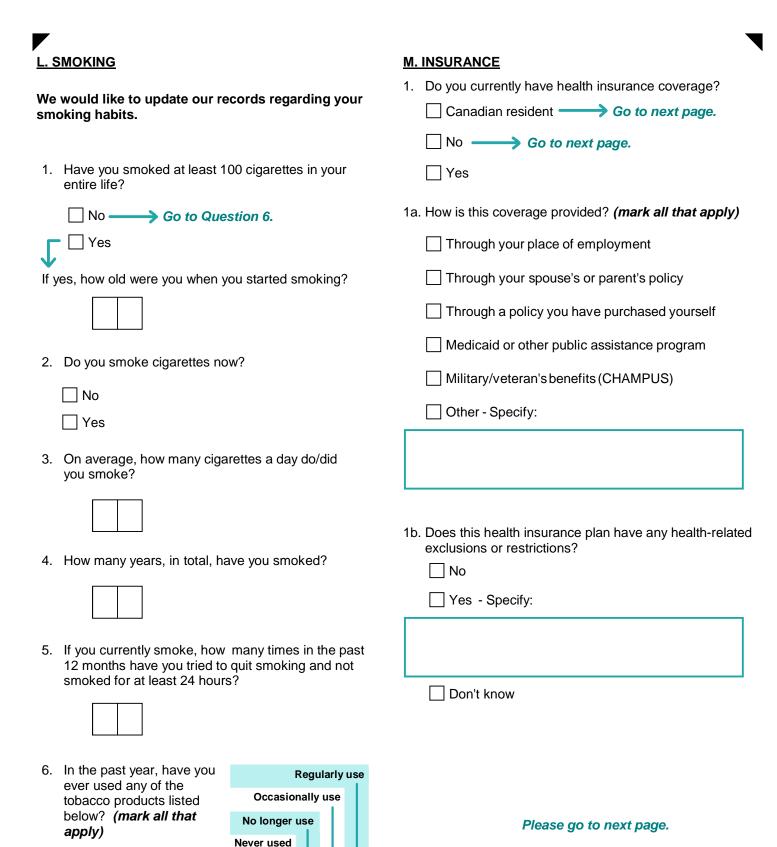
Please go to next page.

Please! Do not mark below this line

12







Please! Do not mark below this line -

Chewing tobacco-----



#### 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:

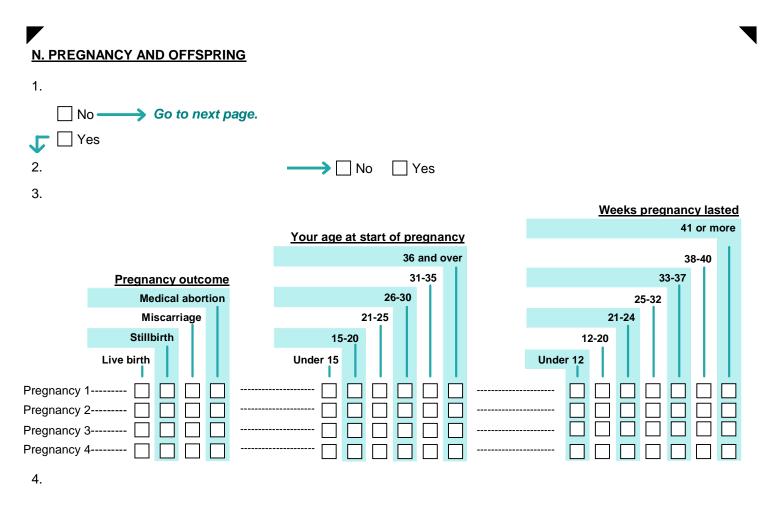
Blindness or difficulty seeing Crossed eyes (strabismus) Eyes different colors Hare lip (cleft lip) Hole in roof of mouth (cleft palate) Absent, fused or extra fingers or toes Hip displacement Diverted urinary stream (hypospadias) Undescended testicle (cryptorchism) Deafness or imparied hearing Shortened 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		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 HEALTH e questions on this page are about your general dental	Not sure Yes	lf yes, age when first occurred	Have y received for this in <u>last 2 ye</u>	care n the
	Ith and any dental care you may have received.	No			No
1. 2. 3.	Had one or more missing teeth because they did not develop?				
	Had difficulty in producing saliva (dry mouth) that required treatment such as artificial saliva? Had severe gingivitis or gum disease requiring surgery or deep cleaning?				
7. 8.					
10 11	Lost 6 or more teeth due to decay or gum disease? . Worn a dental bridge (for missing or removed teeth)? . Worn removable dentures (complete or partial upper or lower or both)? . Worn a prosthesis to lift your palate to improve the quality of your voice?				
13	. Had other dental treatment or surgery? Type of procedure:				
14	. Had any other dental problems? <i>If yes</i> , specify: <i>(Please list any other dental procedures on an extra page)</i>				
15	. Have you ever had dental braces? 17. Have you vis No Yes Don't know No	sited the dentis r for any reaso		clinic with	hin
16	. Do you currently have dental insurance? ☐ No ☐ Yes ☐ Don't know ☐ No ☐	ad your teeth c ental hygienist			
	Please! Do not mark below 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							
<ul> <li>(d) Bisphosphonate drugs like alendronate, fosamax, actol, risdronate, or pamidronate</li> </ul>							
(e) Sodium fluoride							
(f) Calcitonin (calcimar, miacalcin)							
(g) Other Specify:							
		Net					
Avascular necrosis (AVN) is a condition in which		Yes	sure		Currently		
blood supply to the bone joints becomes interrupted, causing that part of the bone to die.	No			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							

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

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

🗌 No —	$\rightarrow$	Go to Section S.
▶ Ves		

What was the name of this disease?

#### Where was this diagnosed?

Doctor's name

Hospital or clinic

Address

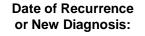
City, State, Zipcode

Was this a:

Recurrence of a previoius diagnosis

New cancer, leukemia, tumor, or similar illness

] Don't know



Month (mm) Yea



#### S. HOSPITALIZATIONS

1. We are also interested in any visits to the hospital for illness, surgical, or diagnostic procedures, including psychiatric hospitalization or short stays of 24 hours or less that you may have had since

#### 2. Since

have you been admitted to a hospital?



3. Since how many times have you been admitted to a hospital?



What was the reason for the first hospitalization?

What procedures/surgeries were performed?

#### Where was this procedure performed?

Hospital or clinic

Address

City, State, Zipcode

Doctor's name

# If you had additional hospitalizations, please attach a separate page

## T. INCOME

1.	household you live in?		Over the last year, w	er the last year, what was your personal income?		
	<ul> <li>Less than \$19,999</li> <li>\$20,000 - \$39,999</li> <li>\$40,000 - \$59,999</li> <li>\$60,000 - \$79,999</li> </ul>	<ul> <li>\$80,000 - \$99,999</li> <li>Over \$100,000</li> <li>Don't know</li> </ul>		Less than \$19,99 \$20,000 - \$39,99 Over \$100,000		☐ \$60,000 - \$79,999 ☐ \$80,000 - \$99,999
2.	During the past year, how household were supported 1 6 2 7 3 8 4 9 or more 5					
<u>U.</u>	COMPUTER, INTERNET	USE				
1.	Do you have access to the	Internet?				
	□ No □ Yes ——	Where do you use the Internet? (n	narl	k all that apply)		
		☐ at home ☐ at school ☐	at	work 🗌 library		other, please specify:

Thank you for your responses!

2 Yes

On the next two pages 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, for example, if you received treatment for a cancer or a heart-related illness. 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.

2. On average, how many hours per week do you use the Internet?

Maybe

if this option becomes available?

🗌 No

3. Would you be interested in completing future questionnaires over the internet

Please go to next page.

Please! Do not mark below this line



hours per week



#### HIPAA\* AUTHORIZATION TO USE AND DISCLOSE INDIVIDUAL HEALTH INFORMATION FOR RESEARCH PURPOSES

**1. Purpose.** As a research participant, I authorize Leslie L. Robison, Ph.D. and the researcher's staff to use and disclose my individual health information for the purpose of conducting the research project entitled Long-Term Follow-Up (LTFU) Study, 9104S03650.

**2. Individual Health Information to be Used or Disclosed.** My individual health information that may be used or disclosed to conduct this research includes medical records since the diagnosis of a cardiac condition or a cancer or similar illness.

**3.** Parties Who May Disclose My Individual Health Information. The researcher and the researcher's staff may obtain my individual health information from:

Hospitals:
Clinics:
Other Providers:
Health Plan:,

and from hospitals, clinics, health care providers and health plans that provide my health care during the study.

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

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

6. Right to Revoke. I can change my mind and withdraw this authorization at any time by sending a written notice to Dr. Leslie L. Robison, Pediatrics - University of Minnesota, 420 Delaware St SE, Mayo Mail Code 715, Minneapolis, MN 55455 to inform the researcher of my decision. If I withdraw this authorization, the researcher may only use and disclose the protected health information already collected for this research study. No further health information about me will be collected by or disclosed to the researcher for this study.

**7.** Potential for Re-disclosure. My individual health information disclosed under this authorization may be subject to re-disclosure outside the research study and no longer protected. For example, researchers

<sup>\*</sup>HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

in other studies could use my individual health information collected for this study without contacting me if they get approval from an Institutional Review Board (IRB) and agree to keep my information confidential.

**7A.** Also, there are other laws that may require my individual health information to be disclosed for public purposes. Examples include potential disclosures if required for mandated reporting of abuse or neglect, judicial proceedings, health oversight activities and public health measures.

This authorization does not have an expiration date.

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

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

Printed name of research participant	Date of birth		
Signature of research participant or research participant's personal representative	Date		
Printed name of research participant's personal representative	Description of personal representative's authority to act on behalf of the research participant		

Please go to next page.

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

Correct

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?

Yes —

No No

$\rightarrow$	Your Email Address



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!