LTFU

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

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

e-mail: ccss@epi.umn.edu

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:

Your relationship:

☐ Self ☐ Parent ☐ Other: _____

Today's date: ☐☐ / ☐☐ / ☐☐☐☐
M M D D Y Y Y Y

Please! Do not mark below this line

EDIT CODE FHK

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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.

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

2. Have you ever taken. . .

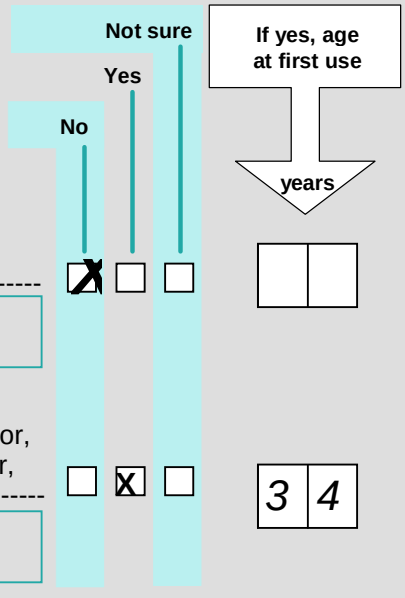
a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil)----------

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



3. When was this condition diagnosed?

0 4 Month (mm)

1 9 9 5 Year (yyyy)

Please! Do not mark below this line

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

1. What is the highest grade or level of schooling you have now completed?

- ☐ 1-8 years (grade school)
- ☐ 9-12 years (high school) but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post graduate level
- ☐ Other - Specify:

2. Which of the following best describes your current marital status?

- ☐ Single
- ☐ Married
- ☐ Living with a partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

3. What is your current living arrangement? ***(mark all that apply)***

- ☐ Live with spouse/partner
- ☐ Live with parent(s)
- ☐ Live with roommate(s)
- ☐ Live with brother(s) and/or sister(s)
- ☐ Live with other relative(s)
- ☐ Live alone
- ☐ Other - Specify

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

- ☐ Working full-time (30 or more hours per week)
- ☐ Working part-time (less than 30 hours per week)
- ☐ Caring for home or family (not seeking paid work)
- ☐ Unemployed and looking for work
- ☐ Unable to work due to illness or disability
- ☐ Retired
- ☐ Student
- ☐ Other - Specify:

If you are not currently working full or part time
→ ***Go to Question 7.***

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:

5a. Main job title:

5b. Please briefly describe the primary tasks in your job:

6. When you are at work, which of the following best describes what you do? Would you say:

- ☐ Mostly sitting or standing
- ☐ Mostly walking
- ☐ Mostly heavy labor or physically demanding work

7. What is your current height without shoes?

☐ Feet ☐☐ Inches

8. What is your current weight without shoes?

☐☐☐ Pounds

Please! Do not mark below this line

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)***

   - ☐ None → ***Go to next page.***
   - ☐ Physician (including osteopath)
   - ☐ Nurse
   - ☐ Chiropractor
   - ☐ Physical therapist
   - ☐ Other - Specify:

2. 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:

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

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

4. Why did you seek medical care? ***(mark all that apply)***

   - ☐ Routine check-up
   - ☐ Specific problem(s) - please specify:

5. Did you discuss any of the following issues with your physician or primary health care provider during any of these visits? ***(mark all that apply)***

   - ☐ None
   - ☐ Heart disease
   - ☐ Osteoporosis (weak or brittle bones)
   - ☐ Risk of developing cancer (breast, skin, other)
   - ☐ Hepatitis C
   - ☐ Dental problems
   - ☐ Fertility issues (ability to get pregnant)
   - ☐ Mental health
   - ☐ Other cancer-related issues - please specify:

Please go to next page.

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)?

- ☐ 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

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
- ☐ 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.

C. SUN SENSITIVITY

1. How would you describe your natural skin color on parts of your body not exposed to the sun?

- ☐ Pale or milky white
- ☐ Very light brown, sometimes freckles
- ☐ Light tan, brown, or olive
- ☐ Brown, dark brown, or black

2. What color are your eyes?

- ☐ Blue
- ☐ Blue-grey
- ☐ Hazel
- ☐ Green
- ☐ Light brown
- ☐ Dark brown/black
- ☐ Mixed/other

3. What is your natural adult hair color? ***(check only one)***

- ☐ Light blond
- ☐ Blond
- ☐ Light brown
- ☐ Medium brown
- ☐ Red-brown
- ☐ Strawberry (reddish) blond
- ☐ Red
- ☐ Dark brown/black
- ☐ Jet black

Sunburn is a reddening of the skin that lasts at least 12 hours after you have been outdoors in the sun.

4. Suppose that after several months of not being in the sun, you went out in the sun without a hat, sunscreen, or protective clothing for an hour. Would you . . . ***(check only one)***

- ☐ Never tan, always burn
- ☐ Sometimes tan, usually burn
- ☐ Usually tan, sometimes burn
- ☐ Always tan, rarely burn

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?

	Never	1-2 times	3-5 times	6+ times
Back and shoulders	☐	☐	☐	☐
Lower limbs	☐	☐	☐	☐
Face or arms	☐	☐	☐	☐
All over	☐	☐	☐	☐

If you are under 21: → ***Go to Question 7.***

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?

Back and shoulders	☐	☐	☐	☐
Lower limbs	☐	☐	☐	☐
Face or arms	☐	☐	☐	☐
All over	☐	☐	☐	☐

7. Have you ever sunbathed or sat outside by the water?

- ☐ No → ***Go to Question 9.***
- ☐ Yes

8. If yes, how many days in the last 12 months have you sunbathed or sat outside by the water?

- ☐ None
- ☐ 1-5 days
- ☐ 6-10 days
- ☐ 11 or more days

9. Have you ever used artificial tanning devices such as a sunlamp, or gone to a tanning booth?

- ☐ No → ***Go to Question 11.***
- ☐ Yes

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?

- ☐ None
- ☐ 1-5 days
- ☐ 6-10 days
- ☐ 11 or more days

11. When you were outside last summer for more than 15 minutes, how often did you protect yourself from the sun by . . .

	Never	Rarely	Sometimes	Often	Always
Applying a sunscreen with a sun protection factor (SPF) of 15 or more on all sun exposed skin areas	☐	☐	☐	☐	☐
Wearing protective clothing such as long-sleeved shirts and long pants	☐	☐	☐	☐	☐
Wearing a hat	☐	☐	☐	☐	☐
Limiting exposure to the sun during the mid-day hours	☐	☐	☐	☐	☐
Staying in the shade	☐	☐	☐	☐	☐

12. Has a medical doctor or nurse ever examined all or most of your skin for signs of skin cancer, not just looked at a certain spot?

- ☐ No
- ☐ Yes
- ☐ Don't know

13. Have you ever had a health care professional remove a skin growth?

- ☐ No
- ☐ Yes

Please! Do not mark below this line

14. Have you ever been told that you had skin cancer? This includes basal cell, squamous cell, and melanoma.

☐ No → *Go to Section D Question 1, below.*

☐ Yes

What was the name of the disease?

Where was the skin cancer located on your body?

When was this diagnosed? ☐☐ ☐☐☐☐

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 (*for example*, between 1980 and 1983).

Where was this diagnosed?

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

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

☐ No → *Go to Question 5.*

☐ Yes

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

☐ Days per week

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

☐☐☐ Minutes per day

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

☐ No → *Go to next page.*

☐ Yes

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

☐ Days per week

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

☐☐☐ Minutes per day

Please! Do not mark below this line

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 PAST 4 WEEKS. 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. Compared to one year ago, 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 activities? If so, how much? ***(check one response on each line)***

	No, not limited at all	Yes, limited a little	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 past 4 weeks, 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)***

	No	Yes
13. Cut down the **amount of time** you spend on work or other activities	☐	☐
14. **Accomplished less** than you would like	☐	☐
15. Were limited in the **kind** of work or other activities	☐	☐
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	☐	☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? ***(check one response on each line)***

	No	Yes
17. Cut down the **amount of time** you 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 past 4 weeks, to what extent has your **physical health** or **emotional problems** interfered with your normal social activities with family, friends, neighbors, or groups? ***(mark one)***

    ☐ Not at all ☐ Quite a bit

    ☐ Slightly ☐ Extremely

    ☐ Moderately

21. How much body pain have you had during the past 4 weeks? ***(mark one)***

    ☐ None ☐ Moderate

    ☐ Very mild ☐ Severe

    ☐ Mild ☐ Very severe

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

    ☐ Not at all ☐ Quite a bit

    ☐ A little bit ☐ Extremely

    ☐ Moderately

Please! Do not mark below this line

F. HEALTH AND WELL-BEING

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

How much of the time during the past 4 weeks . . .

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1. Did you feel full of pep?	☐	☐	☐	☐	☐	☐
2. Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
3. Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
4. Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
5. Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
6. Have you felt downhearted and blue?	☐	☐	☐	☐	☐	☐
7. Did you feel worn out?	☐	☐	☐	☐	☐	☐
8. Have you been a happy person?	☐	☐	☐	☐	☐	☐
9. Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your **physical health** or **emotional problems** interfered with your social activities (like visiting friends, relatives, etc.)? ***(mark one)***

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

How true or false is each of the following statements for you? ***(check one response on each line)***

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11. I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
12. I am as healthy as anybody I know	☐	☐	☐	☐	☐
13. I expect my health to get worse	☐	☐	☐	☐	☐
14. My health is excellent	☐	☐	☐	☐	☐

G. FEELINGS/EMOTIONS

The next set of questions relate to the past 7 days. Below is a list of problems people sometimes have. Please read each one carefully and mark the box that best describes how much that problem has distressed or bothered you during the past 7 days including today. ***Mark only one answer for each problem and do not skip any items.***

	Not at all	A little bit	Moderately	Quite a bit	Extremely
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 reason	☐	☐	☐	☐	☐
6. Feeling lonely	☐	☐	☐	☐	☐
7. Feeling blue	☐	☐	☐	☐	☐
8. Feeling no interest in things	☐	☐	☐	☐	☐
9. Feeling fearful	☐	☐	☐	☐	☐
10. Nausea or upset stomach	☐	☐	☐	☐	☐
11. Trouble getting your breath	☐	☐	☐	☐	☐
12. Numbness or tingling in parts of your body	☐	☐	☐	☐	☐
13. Feeling hopeless about the future	☐	☐	☐	☐	☐
14. Feeling weak in parts of your body	☐	☐	☐	☐	☐
15. Feeling tense or keyed up	☐	☐	☐	☐	☐
16. Spells of terror or panic	☐	☐	☐	☐	☐
17. Feeling so restless you couldn't sit still	☐	☐	☐	☐	☐
18. Feelings of worthlessness	☐	☐	☐	☐	☐

19. Do you currently have pain?

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

20. Do you currently have anxieties/fears as a result of your brother's/sister's illness, or its treatment?

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

Please! Do not mark below this line

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.
I am influenced to a VERY SMALL degree as a result of my brother's/sister's illness.
I am influenced to a SMALL degree as a result of my brother's/sister's illness.
I am influenced to a MODERATE degree as a result of my brother's/sister's illness.
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 illness.

	No influence	Very small influence	Small influence	Moderate influence	Great influence	Very great 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	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

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.)

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

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

☐ 10
☐ 9
☐ 8
☐ 7
☐ 6
☐ 5
☐ 4
☐ 3
☐ 2
☐ 1

2. On which step would you have stood five years ago?

☐ 10
☐ 9
☐ 8
☐ 7
☐ 6
☐ 5
☐ 4
☐ 3
☐ 2
☐ 1

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

☐ 10
☐ 9
☐ 8
☐ 7
☐ 6
☐ 5
☐ 4
☐ 3
☐ 2
☐ 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 the past 6 months. Please complete all items. Please think about yourself as you read these statements and mark one response on each line:

	Never a problem	Sometimes a problem	Often a problem
1. I get upset easily	☐	☐	☐
2. It takes me longer to complete my work	☐	☐	☐
3. I don't think of consequences before acting	☐	☐	☐
4. I am disorganized	☐	☐	☐
5. I forget instructions easily	☐	☐	☐
6. I have problems completing my work	☐	☐	☐
7. I have difficulty recalling things I had previously learned (e.g., names, places events, activities)	☐	☐	☐
8. I get frustrated easily	☐	☐	☐
9. My mood changes frequently	☐	☐	☐
10. I have difficulty coming up with different ways of solving a problem	☐	☐	☐
11. I am impulsive	☐	☐	☐
12. I have trouble finding things in my bedroom, closet or desk	☐	☐	☐
13. I forget what I am doing in the middle of things	☐	☐	☐
14. I have problems getting started on my own	☐	☐	☐
15. I am an underachiever	☐	☐	☐
16. I am easily overwhelmed	☐	☐	☐
17. I have trouble doing more than one thing at a time	☐	☐	☐
18. I blurt things out	☐	☐	☐
19. My desk/workspace is a mess	☐	☐	☐
20. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.)	☐	☐	☐
21. I have trouble prioritizing my activities	☐	☐	☐
22. I read slowly	☐	☐	☐
23. I am slower than others when completing my work	☐	☐	☐
24. I have trouble solving math problems in my head	☐	☐	☐
25. I don't work well under pressure	☐	☐	☐

Please! Do not mark below this line

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K. FEELINGS ABOUT ILLNESS

Below is a list of problems that people sometimes experience when they have a 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 the past month. Rate each problem with respect to having a brother or sister with cancer or a similar illness.

	Not at all or only one time	Once in a while	Half the time	Almost always
1. Having upsetting thoughts or images about your brother's or sister's illness that came into your head when you didn't want them	☐	☐	☐	☐
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 example, feeling scared, angry, sad, guilty, etc.)	☐	☐	☐	☐
5. Experiencing physical reactions when you were reminded of your brother's or sister's illness (for 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 illness	☐	☐	☐	☐
8. Not being able to remember an important part of your experience with your brother's or sister's illness	☐	☐	☐	☐
9. 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 feelings)	☐	☐	☐	☐
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	☐	☐	☐	☐
15. Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)	☐	☐	☐	☐
16. Being overly alert (for example, checking to see who is around you, being uncomfortable with 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.

L. SMOKING

We would like to update our records regarding your smoking habits.

1. Have you smoked at least 100 cigarettes in your entire life?

   ☐ No → ***Go to Question 6.***

   ☐ Yes

   If yes, how old were you when you started smoking?

   ☐☐

2. Do you smoke cigarettes now?

   ☐ No

   ☐ Yes

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

   ☐☐

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

   ☐☐

5. If you currently smoke, how many times in the past 12 months have you tried to quit smoking and not smoked for at least 24 hours?

   ☐☐

6. In the past year, have you ever used any of the tobacco products listed below? ***(mark all that apply)***

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

M. INSURANCE

1. Do you currently have health insurance coverage?

   ☐ Canadian resident → ***Go to next page.***

   ☐ No → ***Go to next page.***

   ☐ Yes

1a. How is this coverage provided? ***(mark all that apply)***

☐ Through your place of employment

☐ Through your spouse's or parent's policy

☐ Through a policy you have purchased yourself

☐ Medicaid or other public assistance program

☐ Military/veteran's benefits (CHAMPUS)

☐ Other - Specify:

1b. Does this health insurance plan have any health-related exclusions or restrictions?

☐ No

☐ Yes - Specify:

☐ Don't know

Please go to next page.

FAMILY HISTORY INFORMATION

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

Cancer

Any diagnosis of cancer or malignant tumor, such as:

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

Conditions Present at Birth

Any abnormality present at birth, such as:

Blindness or difficulty seeing
Crossed eyes (strabismus)
Eyes different colors
Hare lip (cleft lip)
Hole in roof of mouth (cleft palate)
Absent, fused or extra fingers or toes
Hip displacement
Diverted urinary stream (hypospadias)
Undescended testicle (cryptorchism)
Deafness or 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

N. PREGNANCY AND OFFSPRING

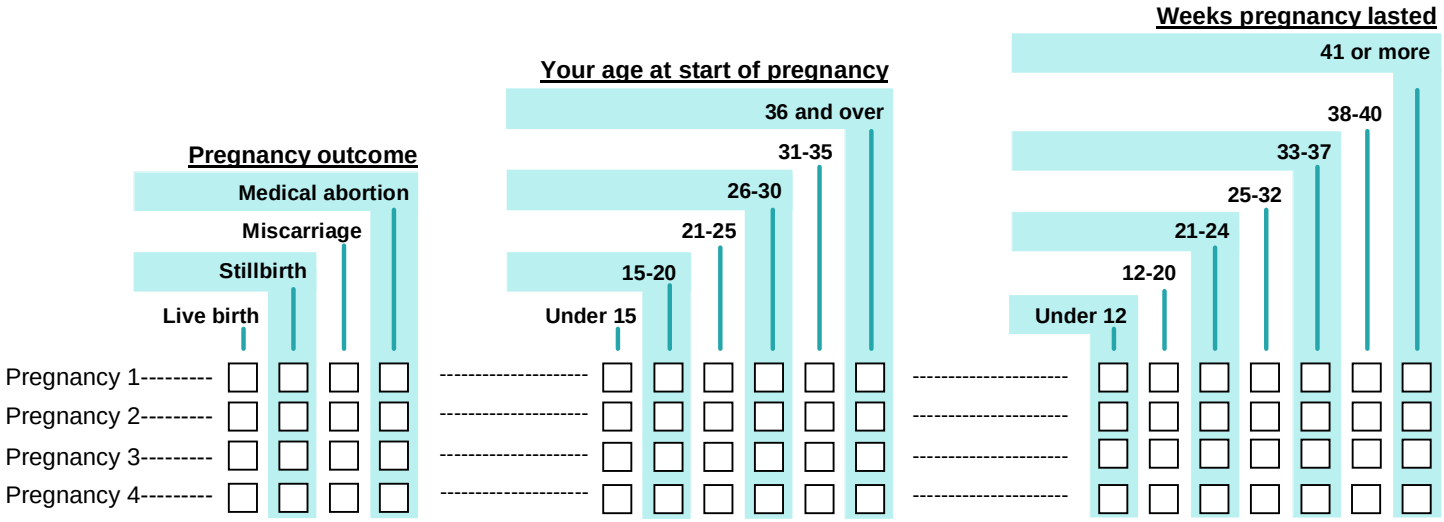
1.

☐ No → *Go to next page.*

☐ Yes

2. → ☐ No ☐ Yes

3.



4.

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 ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			
	☐ Male ☐ Female		☐ Alive ☐ Dead			

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 biological children of this parent.					

Please! Do not mark below this line

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O. DENTAL HEALTH

The questions on this page are about your general dental health and any dental care you may have received.

Have you ever . . .

	No	Yes	Not sure	If yes, age when first occurred	Have you received care for this in the last 2 years? Yes	No
1. Had one or more missing teeth because they did not develop?	☐	☐	☐	☐☐	☐	☐
2. Had a lack of or decreased amount of enamel on surface of teeth (hypoplasia)?	☐	☐	☐	☐☐	☐	☐
3. Had abnormal shaped (small or malformed) teeth?	☐	☐	☐	☐☐	☐	☐
4. Had abnormal root development?	☐	☐	☐	☐☐	☐	☐
5. Had difficulty in producing saliva (dry mouth) that required treatment such as artificial saliva?	☐	☐	☐	☐☐	☐	☐
6. Had severe gingivitis or gum disease requiring surgery or deep cleaning?	☐	☐	☐	☐☐	☐	☐
7. Had root canal therapy?	☐	☐	☐	☐☐	☐	☐
8. Had more than 5 cavities?	☐	☐	☐			
9. Lost 6 or more teeth due to decay or gum disease?	☐	☐	☐			
10. Worn a dental bridge (for missing or removed teeth)?	☐	☐	☐	☐☐	☐	☐
11. Worn removable dentures (complete or partial upper or lower or both)?	☐	☐	☐	☐☐	☐	☐
12. 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?	☐	☐	☐	☐☐	☐	☐
If yes, specify:						

(Please list any other dental procedures on an extra page)

15. Have you ever had dental braces?

☐ No ☐ Yes ☐ Don't know

16. Do you currently have dental insurance?

☐ No ☐ Yes ☐ Don't know

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

☐ No ☐ Yes ☐ Don't know

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

☐ No ☐ Yes ☐ Don't know

Please! Do not mark below this line

P. BONE HEALTH

The questions on this page are about problems that can occur with bone health.

Osteoporosis is a condition in which bones become weak and can sometimes fracture too easily.

	No	Yes	Not sure	If yes, age when first occurred	Currently receiving care for this?	No longer a problem	Still a problem
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)	☐	☐	☐	☐☐	☐	☐	☐
2. Have you ever taken medications for osteoporosis or osteopenia?	☐	☐	☐				

If no → *Go to Question 4.*

	Currently taking this?
3. Which of the following medicines have you taken for this condition?	
(a) Calcium or vitamin D (rocaltrol)	☐
(b) Estrogen or testosterone	☐
(c) Growth hormone	☐
(d) Bisphosphonate drugs like alendronate, fosamax, actol, risdronate, or pamidronate	☐
(e) Sodium fluoride	☐
(f) Calcitonin (calcimar, miacalcin)	☐
(g) Other	☐

Specify:

Avascular necrosis (AVN) is a condition in which blood supply to the bone joints becomes interrupted, causing that part of the bone to die.

	No	Yes	Not sure	If yes, age when first occurred	Currently receiving care for this?	No longer a problem	Still a problem
4. Have you ever been told that you have avascular necrosis (also known as osteonecrosis)?	☐	☐	☐	☐☐	☐	☐	☐
5. Have you ever received treatments for avascular necrosis?	☐	☐	☐				

If no → *Go to next page.*

If no → *Go to next page.*

	Currently receiving this?
6. Which of the following treatments have you received for AVN?	
(a) Medications	☐
(b) Physical therapy	☐
(c) Joint injection	☐
(d) Surgery	☐
(e) Other	☐

Specify:

Please! Do not mark below this line

Q. MEDICATIONS

Please indicate all medicines/drugs you took regularly during the two-year period between
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 medicine/drugs that you buy off the shelf at the drugstore

	No	Yes	Not sure	If yes, age at first use (years)
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				
5. 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				
7. 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.				

Please! Do not mark below this line

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 → *Go to Section S.*

☐ Yes

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

Date of Recurrence or New Diagnosis:

Month (mm) Year (yyyy)

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?

☐ No → *Go to next page.*

☐ Yes

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

Please! Do not mark below this line

T. INCOME

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

- ☐ Less than $19,999
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999
- ☐ Over $100,000
- ☐ Don't know

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

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

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

- ☐ None
- ☐ Less than $19,999
- ☐ $20,000 - $39,999
- ☐ Over $100,000
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999

U. COMPUTER, INTERNET USE

1. Do you have access to the Internet?

☐ No ☐ Yes → Where do you use the Internet? ***(mark all that apply)***

☐ at home ☐ at school ☐ at work ☐ library ☐ other, please specify:

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

3. Would you be interested in completing future questionnaires over the internet if this option becomes available?

☐ Yes ☐ No ☐ Maybe

Thank you for your responses!

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.

Please go to next page.

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

_____

*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.

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

Please give us your correct address or location:

Address	
City	State
Zip Code	Phone Number

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

Name	
Address	Relationship to you
City	State
Zip Code	Phone Number

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

☐ No ☐ Yes → Your Email Address

Please! Do not mark below this line

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Use this space for any additional comments you may have:

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

Mail to:

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

Thank you!

Please! Do not mark below this line

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