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

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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

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	INCORRECT
Grape	Grape

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. . .

	No	Yes	Not sure	If yes, age at first use (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
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?

Month (mm)	Year (yyyy)
04	1995

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 <u>not exposed to the sun?</u>

- ☐ 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?

	Never	1-2 times	3-5 times	6+ times
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
- ☐ 6-10 days
- ☐ 1-5 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
- ☐ 6-10 days
- ☐ 1-5 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

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

☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

20. 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
☐ A little bit
☐ Moderately
☐ Quite a bit
☐ Extremely

Please go to next page.

F. 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	☐	☐	☐	☐

G. 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

H. PREGNANCY AND OFFSPRING

1.

☐ No → ***Go to next page.***

☐ Yes

2. → ☐ No ☐ Yes

3.

	Pregnancy outcome				Your age at start of pregnancy						Weeks pregnancy lasted						
	Live birth	Stillbirth	Miscarriage	Medical abortion	Under 15	15-20	21-25	26-30	31-35	36 and over	Under 12	12-20	21-24	25-32	33-37	38-40	41 or more
Pregnancy 1	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pregnancy 2	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pregnancy 3	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pregnancy 4	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

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

I. 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?	☐	☐	☐	☐☐	☐	☐
14. Had any other dental problems?	☐	☐	☐	☐☐	☐	☐

Type of procedure: ____________________

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

J. 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.***

3. Which of the following medicines have you taken for this condition?	No	Yes	Not sure	Currently taking this?
(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)?---------------------------------------	☐	☐	☐	☐☐	☐	☐	☐

If no → ***Go to next page.***

	No	Yes	Not sure
5. Have you ever received treatments for avascular necrosis?---	☐	☐	☐

If no → ***Go to next page.***

6. Which of the following treatments have you received for AVN?	No	Yes	Not sure	Currently receiving this?
(a) Medications---	☐	☐	☐	☐
(b) Physical therapy---	☐	☐	☐	☐
(c) Joint injection--	☐	☐	☐	☐
(d) Surgery--	☐	☐	☐	☐
(e) Other-- Specify:	☐	☐	☐	☐

Please! Do not mark below this line

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K. 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

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L. 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 M.*
   ☐ 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)

M. 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

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N. 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

O. 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 serious illness such as 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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