Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
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Seattle Children's Hospital & Medical Center
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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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Toll-free phone number:
1-800-775-2167

e-mail:
ccss@epi.umn.edu

Thank you for participating in the Long-Term Follow-Up Study. The information you have already sent is helping us to understand the long-term effects experienced by people who have been treated for cancer, leukemia, tumors, or similar illnesses; it may also help in creating programs to prevent or reduce these events.

In order to continue this work, we need to know how you have been doing since you completed the initial survey. Please fill out the following brief questionnaire to keep us up to date on your health. For some of the questions, we have filled in the information you reported to us previously. If any of this information is incorrect, please correct it in the space provided.

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.

The questions in this booklet relate to:

John Doe

Person completing this questionnaire is:

_____
(Please print your full name)

Your relationship (circle one) Self Parent Other_____

Today's date: _____
(Month/day/year)

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DO NOT WRITE IN THIS AREA

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

MARKING EXAMPLES

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

▶ Incorrect Report

An individual who had attended some college at the time of the first questionnaire, but this was not accurately recorded, would complete Question 1 in the following manner.

1. When you completed the first questionnaire, you indicated that the highest grade or level of schooling that you completed as of December, 1996 was completed high school.

1a. Was this information correct in December, 1996?

○ Yes → Go to Question 1b
● No → Please provide the correct information in the box

Some college

▶ New Information

An individual who, at the age of 25, has been diagnosed with rheumatic heart disease since completing the first questionnaire in December 1996 would complete question 10 in the following manner:

10. Since December, 1996, has a doctor or other health care professional told you that you have or have had:

If yes, age at first occurrence?

	Not sure	Yes	No	Years
HEART AND CIRCULATORY SYSTEM				
1. Rheumatic heart disease?	○	●	○	25
2. Hardening of the arteries or arteriosclerosis?	●	○	○	

▶ New Pregnancy

An individual, currently 28 years old who completed the questionnaire in December, 1996 and has had one pregnancy (or has had someone become pregnant by him) since then, would complete question 8 in the following way:

8. Have you had any pregnancies (or had a woman become pregnant by you) since December, 1996?

● Yes → Go to Question 8a
○ No → Go to Question 9

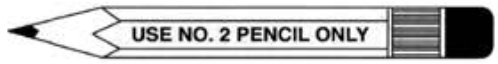
8a. If yes, please fill out the following information for each of your pregnancies (or each time a woman has become pregnant by you), regardless of outcome, since December, 1996.

	Outcome				Your age (years) at beginning of pregnancy						Weeks pregnancy lasted					
	Live birth	Stillbirth	Miscarriage	Medical abortion	Under 15	15 - 20	21 - 25	26 - 30	31 - 35	36 and over	Less than 12 weeks	12 - 24	25 - 32	33 - 37	38 - 40	41 or more weeks
Pregnancy 1	●	○	○	○	○	○	○	●	○	○	○	○	○	○	●	○
Pregnancy 2	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○	○

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

1. **Use the *No. 2 pencil enclosed* (Please do *not* use pen).**
2. **Completely darken your answers, that is, fill in the full circle.**

   CORRECT Ⓐ Ⓑ Ⓒ ● **INCORRECT** ⊗ ✓ ⊙ ◒
3. **Make no stray marks of any kind. Other than your responses, please keep the form as clean as possible. Erase cleanly any answer you wish to change. Do not use "white-out".**



Written responses must stay within the boxes provided.

CORRECT	INCORRECT
grape	grape

Please help us update your information:

When you completed the first questionnaire, you indicated that the highest grade or level of schooling that you completed as of May, 1995 was some college.

1. Was this information correct in May, 1995?

   ○ Yes → Go to Question 1b
   ○ No → Please provide the correct information in the box

. Since May, 1995, have you had any more schooling?

   ○ Yes
   ○ No → Go to Question 2

If yes, what is the highest grade or level of schooling you have completed?

- ○ 1-8 years (grade school)
- ○ 9-12 years (high school) but did not graduate
- ○ Completed high school
- ○ Training after high school, other than college
- ○ Some college
- ○ College graduate
- ○ Post graduate level

2. At our first contact in May, 1995, you indicated that you were separated.

2a. Was this information correct in May, 1995?

   ○ Yes → Go to Question 2b
   ○ No → Please provide the correct information in the box

2b. Since then, has your marital status changed?

   ○ Yes
   ○ No → Go to Question 3

If yes, which of the following best describes your current marital status?

- ○ Single
- ○ Married
- ○ Living as married
- ○ Widowed
- ○ Divorced
- ○ Separated or no longer living as married

3. In the first questionnaire, you indicated that you had previously been employed.

3a. Was this information correct in May, 1995?

   ○ Yes → Go to Question 3b
   ○ No → Please provide the correct information in the box

3b. Since May, 1995, did you work at any time at a job or business, not counting work around the house? (Include unpaid work in the family business or farm.)

   ○ Yes
   ○ No → Go to Question 4

What kind of business or industry best describes your most recent job?

Describe business or industry.

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We wish to obtain more detailed information about you. Please mark any genetic conditions or other conditions that you may have.

GENETIC CONDITIONS

4. Please mark by filling in the circle (either "No", "Yes", or "Not Sure"). Indicate "Yes" only if a physician has told you that you were born with, or have, any of the following conditions.

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

   If you have never heard of these conditions, it is unlikely that you will have had them.

   Have you ever been told by a doctor that you have . . .

	No	Yes	Not sure
a. Ataxia telangiectasia	○	○	○
b. Beckwith-Wiedemann syndrome	○	○	○
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2)	○	○	○
d. Bloom's syndrome	○	○	○
e. Down's syndrome (Mongolism)	○	○	○
f. Fanconi's syndrome	○	○	○
g. Klinefelter's syndrome	○	○	○
h. Multiple exostoses	○	○	○
i. Polyposis coli (Gardner's syndrome)	○	○	○
j. Neurofibromatosis (Type 1)	○	○	○
k. Nevoid basal cell carcinoma syndrome	○	○	○
l. Turner's syndrome	○	○	○
m. Von Hippel-Lindau syndrome	○	○	○
n. Wiskott-Aldrich syndrome	○	○	○
o. Xeroderma pigmentosum	○	○	○
p. Any other genetic disorder	○	○	○

If other, please specify:

CONDITIONS PRESENT AT BIRTH

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

   To the best of your knowledge, were you born with . . .

	No	Yes	Not sure
a. Cleft lip or palate	○	○	○
b. Club foot	○	○	○
c. Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime)	○	○	○
d. Deafness or impaired hearing at birth	○	○	○
e. Blindness or difficulty seeing at birth	○	○	○
f. Eyes different colors or missing an iris (the colored part of the eye)	○	○	○
g. Hydrocephalus (excessive water around or within the brain)	○	○	○
h. Spina bifida or other neural tube defect	○	○	○
i. Unusually small head (microcephaly)	○	○	○
j. Unequal sized limbs (hemihypertrophy)	○	○	○
k. Extra fingers, deformed chest, shortened limbs or any other skeletal abnormality	○	○	○
l. Hole in the heart or other congenital heart defect	○	○	○

If other, please specify:

	No	Yes	Not sure
m. Any congenital abnormality of the pancreas, liver or digestive tract (stomach, intestines)	○	○	○
n. Any kidney, bladder or genital abnormalities	○	○	○
o. Undescended testes	○	○	○
p. Any other birth defects	○	○	○

If other, please specify:

Medications

6. Please indicate all medicines/drugs you took regularly during the two-year period between January 1, 1998, and January 1, 2000. 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 (over-the-counter drugs).

	No	Yes	Not sure
a. ANTIBIOTICS such as amoxicillin, Bactrim, Septra, erythromycin, penicillin, Ceclor or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
b. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
c. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm patch, Premarin, Provera, Medroxyprogesterone or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
d. TESTOSTERONES (MALE HORMONES) such as Delatesteral, Testosterone cypionate, Testosterone enanthate, Testoderm or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
e. THYROID MEDICATIONS such as L-thyroxin, Levothyroid, Levothyroxin, Synthroid or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
f. OTHER MEDICINES TO REPLACE BODY HORMONES such as prednisone, DDAVP (Desmopressin), hydrocortisone, growth hormones or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
g. MEDICATION FOR DIABETES such as Insulin, Diabinese, Glucotrol, Micronase, Tolinase, Glucophage (metformin) or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
h. MUSCLE RELAXANTS such as Baclofen, Flexeril, Valium, Chlorzoxazone (Paraflex) or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
i. PRESCRIBED PAIN MEDICINES such as Tylenol with Codeine (Tylenol #3), Morphine, Percocet, Darvocet, Feldene, Florecet or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			

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	Not sure	Yes	No
j. PRESCRIBED NUTRITIONAL SUPPLEMENTS such as Ferrous Sulfate (Iron), Magnesium, Potassium, Bicitra (Sodium Bicarbonate), Phosphorus (NutraPhos), Vitamin D (Rocalcetrol) or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
k. ANTI-EPILEPTIC (ANTI-SEIZURE) DRUGS such as Dilantin, Phenobarbital, Depakane, Felbatol, Tegretol (Carbamazepine), Klonipen, Primidone (Mysoline), Zarontin or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
l. DRUGS FOR HIGH BLOOD PRESSURE OR FOR YOUR HEART such as Atenolol (Tenoretic), Captopril, Digoxin (Lanoxin), Furosemide (Lasix), Inderal, Methyl-Dopa, Dyazide (Triamterene), Procardia, Vasotec or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
m. PRESCRIBED ANTACIDS (for excess stomach acid or ulcers) such as Tagamet (Cimetidine), Zantac (Ranitidine), Pepsid (Famotidine) or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
n. CHEMOTHERAPY/IMMUNE SUPPRESSANTS such as Cytoxan, Cyclophosphamide, Cyclosporin (CSA), Immuran, Prednisone, Ifosfamide, Methotrexate, FK506 or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
o. ANTIDEPRESSANTS OR OTHER PRESCRIBED DRUGS FOR DEPRESSION, ANXIETY, ATTENTION OR OTHER MOOD DISORDERS such as Elavil, Prozac, Paxil, Zoloft, Navane, Xanax, Ativan, Lithium, Ritalin or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
p. DRUGS FOR RESPIRATORY CONDITIONS such as bronchodilators, allergy medication, Claritin, Alupent, Cromolyn, Beconase or others	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			
q. OTHER PRESCRIBED DRUGS	○	○	○
If yes, specify the name of the drug(s) or indicate you do not know the specific name.			

7. According to our records, you last received radiation treatment for a cancer or similar illness in 1986. Is this information correct?

- ○ No
- ○ Yes → Go to Question 8
- ○ Not sure → Go to Question 8

If no, please indicate any (additional) radiation treatment you received for a recurrence or new cancer.

○ No, did not receive any radiation.

Date of First Treatment

Write the numbers in the boxes. → Month | Year

Please indicate reason for radiation.

Where was the radiation performed?

Hospital:

Address:

City, State:

Doctor's Name:

Date of Second Treatment

Month | Year

If more radiation, please attach a separate piece of paper.

Please indicate reason for radiation.

Where was the radiation performed?

Hospital:

Address:

City, State:

Doctor's Name:

Pregnancy and Offspring

8. Have you had a woman become pregnant by you since May, 1995?

- ○ Yes → Go to Question 8a
- ○ No → Go to Question 9

8a. If yes, please fill out the following information for each time a woman has become pregnant by you, regardless of outcome, since May, 1995.

	Outcome	Your Age (years) at beginning of pregnancy	Weeks pregnancy lasted
	Medical abortion Miscarriage Stillbirth Live birth	36 and over 31 - 35 26 - 30 21 - 25 15 - 20 Under 15	41 or more weeks 38 - 40 33 - 37 25 - 32 12 - 24 Less than 12 weeks
Pregnancy 1	○○○○	○○○○○○	○○○○○○
Pregnancy 2	○○○○	○○○○○○	○○○○○○
Pregnancy 3	○○○○	○○○○○○	○○○○○○
Pregnancy 4	○○○○	○○○○○○	○○○○○○

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FAMILY HISTORY INFORMATION

Conditions or illnesses occurring in family members may be important clues in determining our genetic make-up. This section of the questionnaire deals with cancer, conditions present at birth, and hereditary conditions which 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
Wilms tumor
Lymphoma
Teratoma
Seminoma
Neuroblastoma
Carcinoma
Cancer - Any other type, or location unknown
Skin cancer - please note if melanoma or non-melanoma. (Non-melanoma, also called basal cell or squamous cell carcinoma of the skin, is usually removed in the doctors office, with no further treatment needed.)

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 impaired hearing
Shortened limbs
Club foot
Hole in the heart
Other congenital heart defect
Mongolism (Down's 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

8b. Of the pregnancies you reported on page 7, please write down the names of each of your children who have been born since May, 1995, and indicate whether each child has a history of cancer, a birth defect, and/or any hereditary condition. Please list twin births as two separate children.

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 (refer to list on page 8 and provide specific type)	Age of Onset (yrs.)
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			

8c. Other Parent of Your Children

This section concerns the birth (or biological) parents of your children listed above. Please write the other parent (or parents) of your children.

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 (refer to list on page 8 and provide specific type)	Age of Onset (yrs.)
		○ Alive ○ Dead			
Please list the names of the biological children of this parent.					

If more than one parent, use this space to describe the second parent.

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 (refer to list on page 8 and provide specific type)	Age of Onset (yrs.)
		○ Alive ○ Dead			
Please list the names of the biological children of this parent.					

Attach an additional sheet if needed.

Medical Conditions

9. In your first questionnaire in May, 1995, you reported the following medical condition of the heart or lungs: blood clot, seen a cardiologist, other heart problems, bronchitis, tonsillitis, needed extra oxygen.

Was this information correct in May, 1995?

○ Yes → Go to Question 9a
○ No → Please provide the correct information in the box

9a. Since then, have you been diagnosed with any new illnesses of the heart or lungs?

○ Yes
○ No → Go to Question 12

If yes, please mark by filling out the circle (either "No", "Yes", or "Not Sure"). Answer "Yes" only if a doctor or other health care professional has told you that you have any of the following conditions. In addition, please give your approximate age when you were first told about this condition. (If this illness has occurred more than once, please give age at first time).

10. Since May, 1995, has a doctor or other health care professional told you that you have or have had:

	No	Yes	Not sure	If yes, age at first occurrence? Years
HEART/CIRCULATORY SYSTEM				
a. Rheumatic heart disease?	○	○	○	
b. Hardening of the arteries or arteriosclerosis?	○	○	○	
c. Irregular heartbeat or palpitations (arrhythmia) requiring medication or follow-up by a doctor?	○	○	○	
d. Congestive heart failure or cardiomyopathy (weak heart muscle)?	○	○	○	
e. A myocardial infarction (heart attack)?	○	○	○	
f. Coronary heart disease?	○	○	○	
g. A stroke or a cerebrovascular accident?	○	○	○	
h. Angina pectoris (chest pains due to lack of oxygen to heart requiring medication such as nitroglycerine)?	○	○	○	
i. Pericarditis or fluid around the heart?	○	○	○	
j. Pericardial constriction (scarring or tightness of the sac around the heart)?	○	○	○	
k. Stiff or leaking heart valves?	○	○	○	
l. Heart catheterization ("heart cath")?	○	○	○	
m. Biopsy of the heart muscle?	○	○	○	

11. Since May, 1995, has a doctor or other health care professional told you that you have or have had:

	No	Yes	Not sure	If yes, age at first occurrence? Years
RESPIRATORY SYSTEM				
a. Bronchitis?	○	○	○	
b. Hay fever?	○	○	○	
c. Recurrent sinus infections?	○	○	○	
d. Tonsilitis or enlargement of the tonsils or adenoids?	○	○	○	
e. Pleurisy (inflammation of the lining of the lungs)?	○	○	○	
f. Asthma?	○	○	○	
g. Abnormal chest wall?	○	○	○	
h. Chronic cough or shortness of breath for greater than one month?	○	○	○	
i. Have you had a need for extra oxygen?	○	○	○	
If yes, are you currently using extra oxygen?	○	○	○	
j. Pneumonia, 3 or more times in the past 2 years?	○	○	○	
k. Emphysema?	○	○	○	
l. Lung fibrosis or "scarring" of the lung?	○	○	○	
m. Any other breathing or lung problems?	○	○	○	

If yes, describe this problem.

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12. Since May, 1995, has a doctor or other health care professional told you that you have or have had:

If yes, age at first occurrence?

	Not sure	Yes	No	Years
HEARING/VISION/NERVOUS SYSTEM				
a. Hearing loss requiring a hearing aid?	○	○	○	
b. Deafness in one or both ears not completely corrected by hearing aid?	○	○	○	
c. Complete deafness in either ear?	○	○	○	
d. Legally blind in one or both eyes?	○	○	○	
e. Any other trouble seeing with one or both eyes even when wearing glasses?	○	○	○	
f. Paralysis of any kind?	○	○	○	

If yes, describe this problem.

g. Epilepsy?	○	○	○	
h. Repeated seizures, convulsions, or blackouts?	○	○	○	

If yes, describe this problem.

HEPATITIS

13. Have you ever been told that you tested positive for viral hepatitis?

- ○ Yes
- ○ No

If yes, please indicate which type (mark all that apply):

- ○ Hepatitis A
- ○ Hepatitis B (HBV)
- ○ Hepatitis C (HCV, non A, non B)
- ○ Other types (D, E, F, etc.)
- ○ CMV Hepatitis
- ○ EBV Hepatitis
- ○ Unknown/Not sure

FATIGUE/SLEEPING

14. How true is this statement for you? During the past 30 days, I have felt fatigued (little energy).

- ○ Not at all
- ○ A little bit
- ○ Somewhat
- ○ Quite a lot
- ○ Very much

15. How true is this statement for you? During the past 30 days, I have had problems sleeping (problems either falling asleep or staying asleep).

- ○ Not at all
- ○ A little bit
- ○ Somewhat
- ○ Quite a lot
- ○ Very much

INSURANCE

16. Do you currently have health insurance coverage?

- ○ Canadian Resident → **Go to Question 17**
- ○ No → **Go to Question 17**
- ○ Yes

16a. How is this health insurance 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 dependent/Veteran's benefits (CHAMPUS)
- ○ OTHER *specify*

16b. Does this health insurance plan have any exclusions or restrictions because of your health history?

- ○ Don't know
- ○ No
- ○ Yes *specify*

Cancer, Leukemia, or Tumor

17. Since you first provided information to us in May, 1995, have you been diagnosed with another cancer, leukemia, tumor, or a recurrence (relapse)?

○ Yes
○ No → Go to Question 18

Please write the name of this disease.

Where was this diagnosed?

Hospital:

Address:

City, State:

Doctor's Name:

Was this a:

○ Recurrence of original diagnosis
○ New cancer, leukemia, tumor or similar illness
○ Don't know

Date of Recurrence or New Diagnosis:

Month | Year

17a. If you have had more than one additional cancer, leukemia, tumor, or similar illness since May, 1995, please describe below.

Please write the name of this disease.

Where was this diagnosed?

Hospital:

Address:

City, State:

Doctor's Name:

Was this a:

○ Recurrence of original diagnosis
○ New cancer, leukemia, tumor or similar illness
○ Don't know

Date of Recurrence or New Diagnosis:

Month | Year

18. In this section, we would like to know about any alternative medicine or complementary healing techniques that you have used during the one year period between January 1, 1999 and January 1, 2000. (Mark all that apply.)

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

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Males → Go to Question 21

Females under 18 years of age → Go to Question 21

Menstrual History – for females 18 years or older

The following questions pertain to your menstrual history. Previously we asked a few questions about your menstrual periods. Now we wish to obtain more detailed information. This will help us understand how past treatments affect a woman's pattern of menstruation and the timing of her menopause.

19. Have you ever had a menstrual period naturally; that is, without needing hormones or medication?

- ○ Yes → Go to Question 19a
- ○ No → Skip to Question 20
- ○ Not sure → Go to Question 19a

19a. At what age did you have your first menstrual period?

_____ **years old**

19b. At what age did you last have a menstrual period naturally, without needing medication or hormones to bring it on?

_____ **years old**

19c. Which of the following statements best describes you? (Select only ***one***)

a. ○ I am having regular periods and I **am not** taking birth control pills or female hormones *(example: Premarin, estrogen).*
b. ○ I am having regular periods but I **am** using birth control pills to prevent a pregnancy.
c. ○ My menstrual periods are irregular and I **am** taking birth control pills or female hormones to regulate my periods.
d. ○ I am currently pregnant.
e. ○ I am *not* having menstrual periods naturally but I **am** taking birth control pills or female hormones.
f. ○ I am *not* having menstrual periods naturally and I **am not** taking birth control pills or female hormones.
g. ○ Other, please specify:

If you selected a, b, c, or d, please go to Question 20.
If you selected e, f, or g, please go to Question 19d.

19d. What caused your menstrual periods to stop? (Select only ***one***)

- ○ Normal or early menopause
- ○ Surgery *(example: a hysterectomy)*
- ○ Pregnancy
- ○ Other, please specify:

20. We are conducting a study to better understand the impact of treatments for cancer and other serious illness on how a woman feels about herself and her sexual life. Participation would require 30-40 minutes to complete another questionnaire. Because of the topic, some of the questions are of a personal nature which you may choose not to answer. Would you consider participating?

- ○ Yes
- ○ No
- ○ Not sure

Other Medical Conditions

21. We are also interested in any hospitalizations, including psychiatric hospitalizations, you may have had since you completed the first questionnaire in May, 1995.

21a. Since May, 1995, have you been admitted to a hospital?

- ○ No → Go to Question 22
- ○ Yes

Since May, 1995, how many times have you been admitted to a hospital? _____ times

21b. What was the reason for the first hospitalization?

What procedures/surgeries were performed?

Where was this procedure performed?

Hospital Name:

Address:

City, State:

Doctor's Name:

Date of Hospitalization:

Month | Year

21c. What was the reason for the second hospitalization?

What procedures/surgeries were performed?

Where was this procedure performed?

Hospital Name:

Address:

City, State:

Doctor's Name:

Date of Hospitalization:

Month | Year

(If more than 2 hospitalizations, please include a separate sheet of paper.)

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22. We are also interested in any other serious medical conditions which may have occurred since you completed your last questionnaire. Serious medical conditions would be any medical condition that needs or needed ongoing medical care or treatment from a physician or health care professional. Have you had any serious medical condition that has occurred since May, 1995?

○ No → Go to Question 23
○ Yes

If yes, please provide information about these conditions in the box.

23. Please provide us with your social security number. This information will be kept in the strictest confidence, and will only be used if we have difficulty in contacting you in the future.

☐☐☐ – ☐☐ – ☐☐☐☐

24. We have your current address and phone as:

704 35th Avenue South
Some Place Nice, CO 80000
(123) 555-1212

Do we have your correct address, or are you planning on moving in the next 6 months?

○ Address correct
○ Address is not correct
○ Moving

Could you please give us your new address or location:

Address	
City	**State**
Zip Code	**Telephone #**

25. It would be helpful if you could provide us with the name and address of someone who could give us your new address should you move. We would contact this person only if we are unable to reach you at your home address.

Name	**Relationship to you:**
Address	
City	**State**
Zip Code	**Telephone #**

26. For future planning, if you were given a choice, what are your preferred format(s) for receiving information relating to childhood cancer or similar illnesses? (Mark all that apply.)

- ○ Newsletter
- ○ E-mail
- ○ Chat room
- ○ Internet posting
- ○ No preference
- ○ Not interested in obtaining information
- ○ Other

27. Have you gone on-line looking for information about your cancer or similar illness?

- ○ No
- ○ Yes

How many times?

28. Do you have an e-mail address?

- ○ No
- ○ Yes

e-mail address:

Use this space for any additional comments you may have.

After completing this questionnaire, please return by using the enclosed envelope, and mail to:

Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
1300 S. Second St., Suite 300
Minneapolis, MN 55454-1015

Again, thank you for your help and your participation in this study!

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