<18 years of age

UNIVERSITY OF MINNESOTA

CCRF Epidemiology Research Unit
Division of Epidemiology/Clinical Research
Department of Pediatrics
Suite 300
1300 S. Second St.
Minneapolis, MN 55454

Long-Term Follow-Up Study

of Individuals Treated for Cancer, Leukemia, Tumor or Similar Illness

The questions in this booklet relate to

Person completing this questionnaire is _____
(Please print your full name)

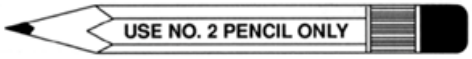
Are you the parent of the child listed above? ○ Yes ○ No → **Specify relationship** _____

The questions in the booklet often refer to "your child". Please answer the questions as if you were the parent of the child listed above.

Today's date _____
(month/day/year)

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 the *No. 2 pencil enclosed* (Please do *not* use pen).



2. Completely darken your answers, that is, fill in the full circle.

CORRECT	INCORRECT
Ⓐ Ⓑ Ⓒ ●	⊗ ✓ ◉ ◔

Written responses must stay within the boxes provided.

CORRECT	INCORRECT
grape	grape

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".

PLEASE DO NOT MARK IN THIS AREA

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[B - C - 18-]

A.1 What is your child's date of birth?

Write the numbers in the boxes. →
Then fill in the matching circles. →

Month	Day	Year
		1 9

A.2 What is his/her sex?

- ○ Male
- ○ Female

A.3 What is his/her social security number?

___ – ___ – ____

- ○ Does not have a social security number

A.4 To which one of the following groups does he/she belong?

- ○ White
- ○ Black
- ○ American Indian or Alaskan Native
- ○ Asian or Pacific Islander
- ○ Other *specify*

A.4a Is he/she Hispanic?

- ○ No
- ○ Yes

A.5 Is he/she a twin?

- ○ No → **Go to Question A.6**
- ○ Yes

A.5a If yes, which type of twin is he/she?

- ○ Identical
- ○ Fraternal (non-identical) same sex
- ○ Fraternal (non-identical) opposite sex
- ○ Not sure what type, same sex

A.6 Was this child adopted?

- ○ No
- ○ Yes

A.7 How many full brothers and sisters (living or dead) does he/she have? Include only those brothers and sisters who have the same birth (biological) mother and father as this child.

A.8 Please describe your child's residence.

- ○ Single family dwelling - unattached (house)
- ○ Single family dwelling - attached (townhouse or condominium)
- ○ Apartment
- ○ Dormitory
- ○ Other *specify*

A.9 Concerning your child's current residence, does he/she:

- ○ Own a residence
- ○ Rent
- ○ Live with parents
- ○ Other *specify*

A.10 What is his/her current height without shoes? ___ feet, and ___ inches

A.11 What is his/her current weight without shoes? ___ pounds

Medical Care

The next questions are about health care received by your child during the 2 year period between July 1, 1992 and June 30, 1994.

B.1 Between July 1, 1992 and June 30, 1994 (2 year period), which of the following health care providers (excluding dentists) were contacted regarding medical care of your child? This includes contacts such as going to a doctor's office, clinic, hospital or telephone calls. (Mark all that apply)

- ○ None → **Go to Question B.8, page 4**
- ○ Physician (including Osteopath)
- ○ Nurse
- ○ Chiropractor
- ○ Physical Therapist
- ○ Other *specify*

B.2 Where did he/she receive their 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
- ○ Other *specify*

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

- ○ 0 times → **Go to Question B.5**
- ○ 1 - 2 times
- ○ 3 - 4 times
- ○ 5 - 6 times
- ○ 7 - 10 times
- ○ 11 - 20 times
- ○ More than 20 times

B.4 As you know, you were asked to participate in this study because your child was once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the physician indicated in question B.3 were related to this previous illness?

- ○ 0 times
- ○ 1 - 2 times
- ○ 3 - 4 times
- ○ 5 - 6 times
- ○ 7 - 10 times
- ○ 11 - 20 times
- ○ More than 20 times

B.5 During this 2 year period, how many times was a doctor's office contacted by telephone, regarding an illness or a medical condition your child may have had?

- ○ 0 times
- ○ 1 - 2 times
- ○ 3 - 4 times
- ○ 5 - 6 times
- ○ 7 - 10 times
- ○ 11 - 20 times
- ○ More than 20 times

B.6 During this 2 year period, how many times was he/she admitted to any hospital?

B.7 During this 2 year period (July 1, 1992 to June 30, 1994), did he/she have any operations or surgeries?

- ○ No
- ○ Yes

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B.8 On these 2 pages, we would like to know about medicines/drugs your child has taken during the 2 year period between July 1, 1992 and June 30, 1994. We are interested in medicine/drugs which he/she has taken consistently for more than one month, or for a total of 30 days in one year. Please list only those drugs prescribed by his/her doctor and filled by a pharmacist. Include pills, syrups, injections, patches, creams.

Please do NOT list medicine/drugs that you buy off the shelf at the drug store (over the counter drugs).

	No	Yes	Not sure
1. ANTIBIOTICS such as amoxicillin, bactrim, erythromycin, penicillin or others	○	○	○
If yes, specify the name of the drug(s).			
2. 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).			
3. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm patch, Premarin, Provera, Medroxyprogesterone or others	○	○	○
If yes, specify the name of the drug(s).			
4. TESTOSTERONES (MALE HORMONES) such as Delatesteral, Testosterone cypionate, enanthate or others	○	○	○
If yes, specify the name of the drug(s).			
5. THYROID MEDICATIONS such as L-thyroxin, Levothyroid, Levothyroxin, Synthroid or others	○	○	○
If yes, specify the name of the drug(s).			
6. 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).			
7. MEDICATION FOR DIABETES such as Insulin, Diabinase, Glucotrol, Micronase, Orinase, Tolinase or others	○	○	○
If yes, specify the name of the drug(s).			
8. MUSCLE RELAXANTS such as Baclofen, Flexeril, Valium, Chlorzoxazone (Paraflex) or others	○	○	○
If yes, specify the name of the drug(s).			
9. PRESCRIBED PAIN MEDICINES such as Tylenol with Codeine (Tylenol #3), Ansaid, Disalcid, Feldene, Fiorecet or others	○	○	○
If yes, specify the name of the drug(s).			
10. 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).			

	No	Yes	Not sure
11. ANTI-EPILEPTIC (ANTI-SEIZURE) DRUGS such as Dilantin, Phenobarbital, Depakane, Tegretol (Carbamazepine), Klonipen, Primidone (Mysoline), Zarontin or others	○	○	○
If yes, specify the name of the drug(s):			
12. DRUGS FOR HIGH BLOOD PRESSURE OR FOR THE HEART such as Atenolol (Tenoretic), Captopril, Digoxin (Lanoxin), Lasix (Furosemide), Inderal, Methyl-Dopa, Dyazide (Triamterene), Procardia, Vasotec or others	○	○	○
If yes, specify the name of the drug(s):			
13. 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):			
14. CHEMOTHERAPY/IMMUNE SUPPRESSANTS such as Cytoxan, Immuran, Prednisone, Ifosfamide or others	○	○	○
If yes, specify the name of the drug(s):			
15. ANTIDEPRESSANTS OR OTHER PRESCRIBED DRUGS FOR DEPRESSION OR OTHER MOOD DISORDERS such as Elavil, Prozac, Paxil, Zoloft, Navane, Ritalin or others	○	○	○
If yes, specify the name of the drug(s):			
16. OTHER PRESCRIBED DRUGS	○	○	○
If yes, specify the name of the drug(s) and reason(s) for use:			

B.9 At the present time, does your child have any of the following?

	No	Yes
Persistent hair loss	○	○
Scarring or disfigurement of the head or neck region (including the face)	○	○
Scarring or disfigurement of the chest or abdomen region	○	○
Scarring or disfigurement of the arms or legs (including an abnormally short arm or leg)	○	○
Walk with a limp	○	○
Loss of an arm, leg, finger or toe	○	○
Loss of an eye	○	○
Other	○	○

specify

DO NOT WRITE IN THIS AREA

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Medical Conditions

The next series of questions relate to medical conditions that have ever occurred in your child's lifetime.

Please indicate, by filling in the circle (either "No", "Yes", or "Not sure") if a doctor or other health care professional has said that your child has any of the following conditions. In addition, please give his/her approximate age when first told about this condition. (If more than one occurrence, please give age at first time.)

Because we need definite responses, it is very important to mark an answer for each question, even if your child has never had that condition. Please do not leave any questions blank (unmarked).

Some questions require a number as well as an answer. Write your answer in the boxes provided and fill in the corresponding circles.

Example

	Not sure	Yes	No	If yes, age at first occurrence? Years
G.1 Hay fever?	○	●	○	
G.2 Recurrent sinus infections or sinus surgery?	○	○	●	6

HEARING/VISION/SPEECH

Has a doctor or other health care professional ever said that your child has or had . . .

	Not sure	Yes	No	If yes, age at first occurrence? Years
C.1 Hearing loss requiring a hearing aid?	○	○	○	
C.2 Deafness in one or both ears not completely corrected by hearing aid?	○	○	○	
C.3 Complete deafness in either ear?	○	○	○	
C.4 Tinnitus or ringing in the ears?	○	○	○	
C.5 Persistent dizziness or vertigo?	○	○	○	
C.6 Problems hearing sounds, words, or language in crowds?	○	○	○	
C.7 Any other hearing problems?	○	○	○	

If yes, describe this problem.

C.8 Legally blind in one or both eyes?	○	○	○	
C.9 Cataracts?	○	○	○	
C.10 Glaucoma (excess pressure in the eyeball)?	○	○	○	
C.11 Problems with double vision?	○	○	○	

Has a doctor or other health care professional ever said that your child has or had . . .

	Not sure	Yes	No	If yes, age at first occurrence? Years
C.12 A detached retina or any other condition of the retina?	○	○	○	

If yes, describe this problem.

C.13 Any other trouble seeing with one or both eyes even when wearing glasses?	○	○	○	
C.14 Very dry eyes requiring eye drops or ointment?	○	○	○	
C.15 Any other eye problems?	○	○	○	

If yes, describe this problem.

C.16 Stammering or stuttering?	○	○	○	
C.17 Any other speech defects?	○	○	○	

If yes, describe this defect.

C.18 Abnormal sense of taste?	○	○	○	
C.19 Loss of taste or smell which has lasted for 3 months or more?	○	○	○	

URINARY SYSTEM

D.1 Kidney stones?	○	○	○	
D.2 REPEATED kidney infections?	○	○	○	
D.3 REPEATED bladder infections?	○	○	○	
D.4 Dialysis?	○	○	○	
D.5 Any other kind of kidney or urinary tract disorder?	○	○	○	

If yes, describe this disorder.

Remember, it is very important that you mark an answer for each of the following questions, even if your child has never had that condition.

Has a doctor or other health care professional ever said that your child has or had . . .

If yes, age at first occurrence?

Not sure | Yes | No

Years

HORMONAL SYSTEMS

E.1 An overactive thyroid gland (hyperthyroid)? . . . . . ○ ○ ○ ☐☐

E.2 An underactive thyroid gland (hypothyroid)? . . . . . ○ ○ ○ ☐☐

E.3 Thyroid nodules? . . . . . ○ ○ ○ ☐☐

E.4 Other thyroid enlargements? . . . . . ○ ○ ○ ☐☐

E.5 Diabetes - that is controlled with diet? . ○ ○ ○ ☐☐

E.6 Diabetes - controlled with pills or tablets? . . . . . ○ ○ ○ ☐☐

E.7 Diabetes - controlled with insulin shots? . . . . . ○ ○ ○ ☐☐

E.8 Deficiency of growth hormone? . . . . . ○ ○ ○ ☐☐

E.9 Has he/she ever received injections of growth hormone (Protropin or Humatrope)? . . . . . ○ ○ ○ ☐☐

E.10 Osteoporosis, brittle, weak or fragile bones? . . . . . ○ ○ ○ ☐☐

E.11 Did he/she need medication to go into puberty? . . . . . ○ ○ ○ ☐☐

E.12 Any other hormonal problems? . . . . . ○ ○ ○ ☐☐

If yes, describe this problem.

E.13 Has a doctor ever said that your child might have trouble having children? . ○ ○ ○ ☐☐

E.14 Has he/she ever had medical tests (such as a blood test, an ultrasound, or sperm count) to see whether or not they might have trouble having children? . . . . . ○ ○ ○ ☐☐

For female children - → Go to Question E.16

E.15 MALES - Has he ever been told he had a low sperm count? . . . . . ○ ○ ○ ☐☐

For male children - → Go to Question F.1

Has a doctor or other health care professional ever said that your child has or had . . .

If yes, age at first occurrence?

Not sure | Yes | No

Years

E.16 FEMALES - Has she ever had a menstrual period? . . . . . ○ ○ ○ ☐☐

If no, → Go to Question F.1

E.17 FEMALES - Is she currently having menstrual periods? . . . . . ○ ○ ○

If no, at what age was her last menstrual period? ☐☐

E.18 Has she ever taken female hormones, including birth control pills (oral contraceptives) to have a period? . . . . . ○ ○ ○ ☐☐

HEART AND CIRCULATORY SYSTEM

F.1 Rheumatic heart disease? . . . . . ○ ○ ○ ☐☐

F.2 Hardening of the arteries or arteriosclerosis? . . . . . ○ ○ ○ ☐☐

F.3 Irregular heartbeat or palpitations, (Arrythmia) requiring medication or follow-up by a doctor? . . . . . ○ ○ ○ ☐☐

F.4 Congestive heart failure or cardio-myopathy (weak heart muscle)? . . . ○ ○ ○ ☐☐

F.5 A myocardial infarction (heart attack)? . . . . . ○ ○ ○ ☐☐

F.6 Coronary heart disease? . . . . . ○ ○ ○ ☐☐

F.7 Hypertension (high blood pressure) NOT requiring medication? . . . . . ○ ○ ○ ☐☐

F.8 Hypertension (high blood pressure) requiring medication? . . . . . ○ ○ ○ ☐☐

F.9 A stroke or a cerebrovascular accident? . . . . . ○ ○ ○ ☐☐

F.10 Angina pectoris (chest pains due to lack of oxygen to heart requiring medication such as nitroglycerine)? . ○ ○ ○ ☐☐

F.11 Pericarditis or fluid around the heart? . . . . . ○ ○ ○ ☐☐

F.12 Pericardial constriction (scarring or tightness of the sac around the heart)? . . . . . ○ ○ ○ ☐☐

F.13 Stiff or leaking heart valves? . . . . . ○ ○ ○ ☐☐

F.14 Heart catheterization ("heart cath")? . ○ ○ ○ ☐☐

F.15 Biopsy of the heart muscle? . . . . . ○ ○ ○ ☐☐

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

Has a doctor or other health care professional ever said that your child has or had . . .

If yes, age at first occurrence?

Not sure | Yes | No | Years

F.16 Blood clot in head, lung, arm, leg, or pelvis? ○○○ ☐☐

F.17 Does exercise cause severe chest pain, shortness of breath, or irregular heart beat in your child? ○○○ ☐☐

F.18 Has your child seen a cardiologist (heart specialist)? ○○○ ☐☐

F.19 Has anyone in your child's immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55? ○○○ ☐☐

F.20 Any other heart or circulatory problems? ○○○ ☐☐

If yes, describe this problem.

For male children → Go to Question G.1

F.21 FEMALES - Has she had heart failure during pregnancy or after delivery? ○○○ ☐☐

RESPIRATORY SYSTEM

G.1 Bronchitis? ○○○ ☐☐

G.2 Hay fever? ○○○ ☐☐

G.3 Recurrent sinus infections? ○○○ ☐☐

G.4 Tonsillitis or enlargement of the tonsils or adenoids? ○○○ ☐☐

G.5 Pleurisy (inflammation of the lining of the lungs)? ○○○ ☐☐

G.6 Asthma? ○○○ ☐☐

G.7 Abnormal chest wall? ○○○ ☐☐

G.8 Chronic cough or shortness of breath for greater than one month? ○○○ ☐☐

G.9 Has your child ever had a need for extra oxygen? ○○○ ☐☐

If yes, is he/she currently using extra oxygen? ○○○

G.10 Pneumonia, 3 or more times in the past 2 years? ○○○ ☐☐

G.11 Emphysema? ○○○ ☐☐

Has a doctor or other health care professional ever said that your child has or had . . .

If yes, age at first occurrence?

Not sure | Yes | No | Years

G.12 Lung fibrosis or "scarring" of the lung? ○○○ ☐☐

G.13 Any other breathing or lung problems? ○○○ ☐☐

If yes, describe this problem.

DIGESTIVE SYSTEM

H.1 Gallstones? ○○○ ☐

H.2 Any other gallbladder trouble? ○○○ ☐

If yes, describe this trouble.

H.3 Cirrhosis of the liver? ○○○ ☐

H.4 Hepatitis? ○○○ ☐

H.5 Jaundice? ○○○ ☐

H.6 Any other liver trouble? ○○○ ☐

If yes, describe this trouble.

H.7 An ulcer? ○○○ ☐

H.8 Any disease of the esophagus? ○○○ ☐

If yes, describe this disease.

H.9 FREQUENT indigestion? ○○○ ☐

H.10 FREQUENT heartburn? ○○○ ☐

If yes, does your child take medication for it more than once a month? ○○○ ☐

H.11 Any other stomach trouble? ○○○ ☐

If yes, describe this trouble.

H.12 Intestinal polyps? ○○○ ☐

H.13 Diverticular disease? ○○○ ☐

H.14 Colitis? ○○○ ☐

H.15 FREQUENT constipation? ○○○ ☐

H.16 Chronic diarrhea? ○○○ ☐

H.17 Rectal or anal fistula? ○○○ ☐

H.18 Rectal or anal stricture (narrowing or scarring)? ○○○ ☐

It is very important that you mark an answer for each of the following questions, even if your child has never had that surgery.

Please indicate if your child has ever had any of the following surgical procedures done. If yes, please give your child's approximate age when this surgery was performed.

If yes, age at first occurrence?

Not sure
Yes
No
Years

SURGICAL PROCEDURES

I.1 Amputation of an arm, leg, hand, foot, finger or toe? ..... ○○○ ☐☐

If yes, specify.

I.2 Scoliosis surgery (insertion of rods or other methods to straighten the spine)? ..... ○○○ ☐☐

I.3 Other surgery of spinal cord or spine? . ○○○ ☐☐

If yes, specify.

I.4 Leg lengthening or shortening procedures? ..... ○○○ ☐☐

I.5 Joint replacement? ..... ○○○ ☐☐

If yes, specify.

I.6 Other bone surgery? ..... ○○○ ☐☐

If yes, specify.

I.7 Coronary artery bypass surgery? ..... ○○○ ☐☐

I.8 Pericardiectomy (stripping of the sac around the heart)? ..... ○○○ ☐☐

I.9 Angioplasty (enlarging a heart vessel using a balloon)? ..... ○○○ ☐☐

I.10 Other heart surgery? ..... ○○○ ☐☐

If yes, specify.

I.11 Surgery for intestinal obstruction (blocked intestines)? ..... ○○○ ☐☐

Please indicate if your child has ever had any of the following surgical procedures done.

If yes, age at first occurrence?

Not sure
Yes
No
Years

I.12 Colostomy or ileostomy (stool going into a bag)? ..... ○○○ ☐☐

I.13 Takedown (reconnection) of the colostomy or ileostomy? ..... ○○○ ☐☐

I.14 Surgery to remove a blood clot in an artery or vein? ..... ○○○ ☐☐

If yes, specify which artery, vein or part of body:

I.15 Removal of the thyroid gland in the neck? ..... ○○○ ☐☐

I.16 Removal of the spleen? ..... ○○○ ☐☐

I.17 Ventriculoperitoneal shunt (tube from the brain to the abdomen (under the skin) which removes excess spinal fluid)? ..... ○○○ ☐☐

I.18 Breast surgery for removal or biopsy of a suspicious lump? ..... ○○○ ☐☐

I.19 A bronchoscopy since his/her therapy stopped? ..... ○○○ ☐☐

I.20 Other lung surgery? ..... ○○○ ☐☐

If yes, specify.

I.21 A liver biopsy since his/her therapy stopped? ..... ○○○ ☐☐

I.22 Reconstructive surgery (surgery to repair damage due to accident or medical therapy or other surgery)? . ○○○ ☐☐

I.23 Heart transplant ..... ○○○

I.24 Lung transplant ..... ○○○ ☐☐

I.25 Kidney transplant ..... ○○○ ☐☐

I.26 Bone marrow transplant ..... ○○○ ☐☐

I.27 Other organ transplant ..... ○○○ ☐☐

If yes, specify transplant.

I.28 Cataract surgery? ..... ○○○ ☐☐

I.29 Sinus surgery? ..... ○○○ ☐☐

I.30 Surgery on the jaw? ..... ○○○ ☐☐

I.31 Any other surgery? ..... ○○○ ☐☐

If yes, specify surgery.

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DO NOT WRITE IN THIS AREA

Just a reminder - it is very important that you mark an answer for each of the following questions, even if your child has never had that condition.

Has a doctor or other health care professional ever said that your child has or had . . .

If yes, age at first occurrence?

Not sure
Yes
No
Years

BRAIN AND NERVOUS SYSTEM

J.1 Cerebral palsy? ..... ○○○ ☐☐
J.2 Paralysis of any kind? ..... ○○○ ☐☐

If yes, describe this problem.

J.3 Mental retardation? ..... ○○○ ☐☐
J.4 Epilepsy? ..... ○○○ ☐☐
J.5 Repeated seizures, convulsions, or blackouts? ..... ○○○ ☐☐

If yes, describe this problem.

J.6 Migraine? ..... ○○○ ☐☐
J.7 Other frequent headaches? ..... ○○○ ☐☐
J.8 Problems with balance, equilibrium, or ability to reach for or manipulate objects? ..... ○○○ ☐☐
J.9 Tremors or problems with movements? ..... ○○○ ☐☐
J.10 Weakness or inability to move arm(s)? ..... ○○○ ☐☐
J.11 Weakness or inability to move leg(s)? ..... ○○○ ☐☐
J.12 Decreased sense of touch or feeling in hands, fingers, arms or legs? ..... ○○○ ☐☐
J.13 Prolonged pain or abnormal sensation in arms, legs, or back? ..... ○○○ ☐☐
J.14 Problems chewing or swallowing solids or liquids? ..... ○○○ ☐☐
J.15 Any other brain or nervous system problems? ..... ○○○ ☐☐

If yes, describe this problem.

SOCIAL FUNCTIONING

J.16 About how many close friends does your child have?

○ 0 → **Go to Question J.18**
○ 1
○ 2 or 3
○ 4 or more

J.17 About how many times a week does your child do things with close friends?

○ Less than 1
○ 1 or 2
○ 3 or more

J.18 Compared to other children of his/her age, how well does your child . . .

Better
About Same
Worse

a. Get along with his/her brothers and sisters? . ○○○
b. Get along with other children? ..... ○○○
c. Behave with his/her parents? ..... ○○○
d. Play and work by himself/herself? ..... ○○○

J.19 How well do the following statements describe your child's behavior?

Not True
Sometimes True
Often True

a. Has sudden changes in mood or feelings .. ○○○
b. Feel or complains that no one loves him/her . ○○○
c. Is rather high strung, tense, or nervous ..... ○○○
d. Cheats or tells lies ..... ○○○
e. Is too fearful or anxious ..... ○○○
f. Argues too much ..... ○○○
g. Has difficulty concentrating, cannot pay attention for long ..... ○○○
h. Is easily confused, seems to be in a fog .... ○○○
i. Bullies, or is cruel or mean to others ..... ○○○
j. Is disobedient at home ..... ○○○
k. Is disobedient at school ..... ○○○
l. Does not seem to feel sorry after he/she misbehaves ..... ○○○
m. Has trouble getting along with other children ..... ○○○
n. Has trouble getting along with teachers .... ○○○
o. Is impulsive, or acts without thinking ..... ○○○
p. Feels worthless or inferior ..... ○○○
q. Is not liked by other children ..... ○○○
r. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions ..... ○○○
s. Is restless or overly active, cannot sit still .. ○○○
t. Is stubborn, sullen, or irritable ..... ○○○
u. Has a very strong temper and loses it easily . ○○○
v. Is unhappy, sad or depressed ..... ○○○
w. Is withdrawn, does not get involved with others ..... ○○○

If child is 12 years of age or older - → Go to Question J.21

J.20 FOR CHILDREN UNDER 12 YEARS OF AGE

	Not True	Sometimes True	Often True
a. Breaks things on purpose, deliberately destroys his/her own things	○	○	○
b. Clings to adults	○	○	○
c. Cries too much	○	○	○
d. Demands a lot of attention	○	○	○
e. Is too dependent on others	○	○	○

If child is under 12 years of age - → Go to Question J.22

J.21 FOR CHILDREN 12 YEARS OF AGE OR OLDER

	Not True	Sometimes True	Often True
a. Feels others are out to get him/her	○	○	○
b. Hangs around with kids who get into trouble	○	○	○
c. Is secretive, keeps things to himself/ herself	○	○	○
d. Worries too much	○	○	○

J.22 In this question, we are only interested in whether your child has had certain medical conditions in the last 12 months. Please indicate whether he/she had any of the following conditions, even if you have mentioned them before.

During the past 12 months, has he/she had:

	NO	YES
Diabetes?	○	○
Epilepsy?	○	○
Repeated seizures, convulsions, or blackouts?	○	○
Repeated kidney infections?	○	○
Migraine?	○	○
FREQUENT headaches?	○	○
Gallstones?	○	○
Cirrhosis of the liver?	○	○
Hepatitis?	○	○
Yellow jaundice?	○	○
An ulcer?	○	○
FREQUENT indigestion?	○	○
Diverticulitis?	○	○
Colitis?	○	○
FREQUENT constipation?	○	○
Bronchitis?	○	○
Hay fever?	○	○
Tonsilitis or enlargement of the tonsils or adenoids?	○	○
Emphysema?	○	○
Pleurisy?	○	○

J.23 Does your child currently have pain as a result of his/her cancer, leukemia, tumor or similar illness, or its treatment?

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

If he/she has pain, where is it? (name all areas)

J.24 Does your child currently have anxieties/fears as a result of his/her cancer, leukemia, tumor or similar 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

CANCER, LEUKEMIA OR TUMORS

As you know, your child was diagnosed with a cancer, leukemia, tumor, or other similar illness. The following questions (K.1 to K.8) relate to the diagnosis of another cancer, leukemia, tumor, or other similar illness, or a recurrence (relapse) of his/her original diagnosis, which has occurred since the first one.

K.1 At any time following this original diagnosis, was your child diagnosed with another cancer, leukemia, tumor or similar illness? (Include any relapse or recurrence of your original diagnosis).

- ○ No → **Go to Question L.1, page 12**
- ○ Yes

K.2 Please write in the name of this disease.

K.3 Where was this diagnosed?

Hospital:

Address:

City, State:

Doctor's Name:

K.4 Was this a:

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

Date of Recurrence or Diagnosis:

Month	Year
	1 9

K.5 Has your child had any additional cancers, leukemias, tumors, or similar illnesses after this second one?

- ○ No → **Go to Question L.1, page 12**
- ○ Yes

K.6 Please write in the name of this disease.

K.7 Where was this diagnosed?

Hospital:

Address:

City, State:

Doctor's Name:

K.8 Was this a:

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

Date of Recurrence or Diagnosis:

Month	Year
	1 9

PLEASE ANSWER THE FOLLOWING QUESTIONS FOR CHILDREN WHO ARE CURRENTLY 12 YEARS OF AGE OR OLDER.

For children younger than 12 years.
→ **Go to Question N.5, page 13**

MARITAL STATUS

L.1 Has your child ever been married or had a live-in relationship (lived as married)?

- ○ No → **Go to Question M.1**
- ○ Yes

L.2 Which of these possibilities best describes your child's current marital status?

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

OFFSPRING/PREGNANCY HISTORY

M.1 To your knowledge, has your child ever been sexually active (had sexual intercourse)?

- ○ Don't know
- ○ No → **Go to Question N.1, page 13**
- ○ Yes

M.2 Is he/she currently sexually active?

- ○ Don't know
- ○ No
- ○ Yes

M.3 Is your daughter currently pregnant or does your son currently have a woman pregnant by him?

- ○ Don't know
- ○ No
- ○ Yes

M.4 Has your daughter ever become pregnant, or has your son ever had a woman become pregnant by him?

- ○ No → **Go to Question N.1, page 13**
- ○ Yes

M.5 Including live births, stillbirths, miscarriages, and abortions, how many times has your daughter become pregnant or has your son had a woman become pregnant by him?

Times

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HEALTH HABITS

Smoking

N.1 To your knowledge, has your child smoked at least 100 cigarettes in his/her entire life?

- ○ Don't know
- ○ No → Go to Question N.2
- ○ Yes

N.1a Does your child smoke cigarettes now?

- ○ No
- ○ Yes

N.2 To your knowledge, has your child ever used any of the tobacco products listed below? (Mark all that apply)

	Yes, regularly use	Yes, occasionally use	Yes, no longer use	Never used
Chewing tobacco?	○	○	○	○
Snuff tobacco?	○	○	○	○
Pipes?	○	○	○	○
Cigars?	○	○	○	○

If yes, to any of the above, how long?

	11+ years	5 - 10 years	3 - 4 years	1 - 2 years	Less than 1 year
Chewing tobacco?	○	○	○	○	○
Snuff tobacco?	○	○	○	○	○
Pipes?	○	○	○	○	○
Cigars?	○	○	○	○	○

Alcohol

N.3 In their entire life, has your child ever had at least 2 drinks of any kind of alcoholic beverage?

- ○ Don't know
- ○ No → Go to Question N.5
- ○ Yes

N.4 To your knowledge, has your child had at least one drink of beer, wine, or liquor during the past year?

- ○ Don't know
- ○ No
- ○ Yes

Physical Activity

N.5 On how many of the past 7 days did your child exercise or do sports for at least 20 minutes that made him/her sweat or breathe hard (e.g. dancing, jogging, basketball, etc.)

- ○ 0 days
- ○ 1 day
- ○ 2 days
- ○ 3 days
- ○ 4 days
- ○ 5 days
- ○ 6 days
- ○ 7 days

N.6 Because of any impairment or health problems, does your child need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around their home?

- ○ No
- ○ Yes

N.7 Because of any impairment or health problems, does your child need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes.

- ○ No
- ○ Yes

N.8 Does any impairment or health problem keep your child from attending school or holding a job?

- ○ No
- ○ Yes

N.9 If your child is 16 years of age or older, do they currently have a driver's license?

- ○ No
- ○ Yes
- ○ Not over 16 years old

N.10 Over the last 2 years, how long (if at all) has your child's health limited them in each of the following activities? (Mark one circle on each line)

	Not limited at all	Limited for 3 months or less	Limited for more than 3 months
a. The kinds or amounts of vigorous activities he/she can do, like lifting heavy objects, running or participating in strenuous sports	○	○	○
b. The kinds or amounts of moderate activities he/she can do, like moving a table, carrying groceries or bowling	○	○	○
c. Walking uphill or climbing a few flights of stairs	○	○	○
d. Bending, lifting or stooping	○	○	○
e. Walking one block	○	○	○
f. Eating, dressing, bathing, or using the toilet	○	○	○

Health Practices

N.11 Would you say that your child's health is:

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor

N.12 Some people get a general physical examination from a doctor once in a while even though they *are feeling well and have not been sick.* When was the last time your child had a general physical examination when he/she was not sick?

- ○ Less than 1 year ago
- ○ 1 - 2 years ago
- ○ 3 - 4 years ago
- ○ 5 or more years ago
- ○ Never

N.13 How long has it been since your child last went to a dentist?

- ○ Less than 1 year ago
- ○ 1 - 2 years ago
- ○ 3 - 4 years ago
- ○ 5 or more years ago
- ○ Never

SCHOOL HISTORY

O.1 What is the highest grade or level of schooling that your child has 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

O.2 If your child completed high school, did he/she receive a regular high school diploma or receive a high school equivalency certificate, also called a GED?

- ○ Standard diploma
- ○ GED

O.3 In elementary, junior, or high school was your child ever in any of the following programs? (Mark all that apply)

	No	Yes	Not sure
Learning disabled or special education program?	○	○	○
If yes, was your child in the program because of:			
- missed school	○	○	○
- low scores on tests	○	○	○
- *problems learning or concentrating*	○	○	○
- emotional or behavioral problems	○	○	○
Advanced placement or talented program?	○	○	○
Homebound education for at least one school year?	○	○	○

O.4 If your child was in a learning disabled or special education program, what grades was he/she in at that time? (Mark all that apply)

○ K	○ 4th	○ 7th	○ 10th
○ 1st	○ 5th	○ 8th	○ 11th
○ 2nd	○ 6th	○ 9th	○ 12th
○ 3rd			

O.5 During the last school year, how many days of school did your child miss because of illness or doctor's appointments? (Do not include time missed for vacation, travel, etc.)

0	0	0
1	1	1
2	2	2
3	3	3
4	4	4
5	5	5
6	6	6
7	7	7
8	8	8
9	9	9

EMPLOYMENT HISTORY

O.6 Has your child ever had a job?

- ○ No → Go to page 15
- ○ Yes

O.7 *During the last 12 months,* did he/she 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

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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 child or in your child's family members. 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
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

Please complete this section on all members of your child's family. It is very important that you include everyone, even those family members who did not have conditions listed on the previous page.

- **If a family member has had a history of cancer, a birth defect and/or one of the hereditary conditions listed on the previous page, please write the type of cancer, birth defect, or hereditary condition into the spaces provided. Include all stillborn children (a stillbirth is a pregnancy more than 20 weeks). Fill out the medical history section whether this person is alive or dead. If the person died of another cause (like an accident) and never had any of these illnesses, or if the person is still living and does not have any of these, write NONE in the medical history section. Enter "0" for age at onset if present at birth or found in the first year of life.**

EXAMPLE OF FAMILY HISTORY

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.)
John Paul Smith	● Male ○ Female	5/11/51	● Alive ○ Dead		None	
Sharon Marie Smith	○ Male ● Female	6/29/55	○ Alive ● Dead	11/5/90	Leukemia	29
Peter Quintin Smith	● Male ○ Female	2/15/62	● Alive ○ Dead		Aniridia Wilms Tumor	0 3
Unnamed (stillbirth)	○ Male ● Female	4/20/63	○ Alive ● Dead	4/20/63	None	

P.1 YOUR CHILD

Full Name (First, Middle, Last)	Sex	Date of Birth (Mo/Day/Yr)	Medical History of Cancer, Birth Defect, Hereditary Condition (provide specific type)	Age of Onset (yrs.)
	○ Male ○ Female			

P.2 YOUR CHILD'S FULL BROTHERS AND SISTERS (those with the same mother and father)

- **Please write in the name of all of your child's brothers and sisters (living or dead) in this section, whether they have had one of these conditions or not.**

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			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			

(If you need more space, please use a separate sheet of paper, and attach it to this page.)

Please go on to the next page

P.3 CHILD'S PARENTS

- **This section concerns your child's birth (biological) parents. Please use this section to record any cancers, birth defects and/or hereditary conditions which have occurred in his/her parents (if any).**

Full Name (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.)
Mother		○ Alive ○ Dead			
Father		○ Alive ○ Dead			

YOUR CHILD'S HALF-BROTHERS AND HALF-SISTERS (IF ANY)

- **If your child does not have half-brothers or half-sisters** → Go to Question P.6, page 18

- **This section concerns your child's half-brothers and half-sisters (if any). Please list all half-brothers and half-sisters and record cancers, birth defects and/or hereditary conditions which have occurred. Please follow the instructions given on the top of the previous page.**

P.4 OTHER CHILDREN OF CHILD'S MOTHER

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			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			

P.5 OTHER CHILDREN OF CHILD'S FATHER

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			
	○ Male ○ Female		○ Alive ○ Dead			
	○ Male ○ Female		○ Alive ○ Dead			

Attach an additional sheet if needed.

P.6 Does your child have any more distant relatives, such as grandparents, cousins, aunts, uncles, nieces or nephews who had cancer before they were 45 years old?

- ○ No → **Go to Question Q.1**
- ○ Yes

If yes, write in the name, relationship to your child, the type of cancer and age when this relative had cancer.

Full Name	Relationship To You	Side of Family	Type Of Cancer	Age When Cancer Occurred
		○ Mother ○ Father		
		○ Mother ○ Father		
		○ Mother ○ Father		
		○ Mother ○ Father		
		○ Mother ○ Father		

INSURANCE

Q.1 Have you ever had difficulty in obtaining health insurance for your child because of his/her health history?

- ○ No
- ○ Yes

Q.2 Does your child currently have health insurance coverage?

- ○ Canadian Resident → **Go to Question Q.4**
- ○ No → **Go to Question Q.4**
- ○ Yes

Q.3 How is this health insurance provided? (Mark all that apply)

- ○ Through parent's place of employment
- ○ Through parent's policy
- ○ Through a policy you have purchased for your child
- ○ Medicaid or other public assistance program
- ○ Military dependant/Veteran's benefits (CHAMPUS)
- ○ Other *specify*

Q.3a Does this health insurance plan have any exclusions or restrictions because of your child's health history?

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

Q.3b Is there an extra premium charge on this health insurance policy because of your child's health history?

- ○ Don't know
- ○ No
- ○ Yes

Q.4 Have you ever had difficulty in obtaining life insurance for your child because of his/her health history?

- ○ No
- ○ Yes
- ○ Never tried to obtain life insurance

Q.5 Does he/she currently have life insurance coverage?

- ○ No → **Go to Question Q.7, page 19**
- ○ Yes

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Q.6 How is this life insurance provided? (Mark all that apply)

- ○ Through parent's place of employment
- ○ Through parent's policy
- ○ Through a policy you have purchased for this child
- ○ Other *specify*

Q.6a Does this life insurance plan have any exclusions or restrictions?

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

Q.6b Is there an extra premium charge on your child's life insurance policy because of his/her health history?

- ○ Don't know
- ○ No
- ○ Yes

Q.6c What is the total dollar value of your child's life insurance policy(ies)?

- ○ Under $10,000
- ○ $10,000 - $49,999
- ○ $50,000 - $99,999
- ○ $100,000 or more
- ○ Don't know

RELIGION

Q.7 What religion do you consider your child to be? (Mark all that apply.)

- ○ None
- ○ Catholic
- ○ Lutheran
- ○ Baptist
- ○ Presbyterian
- ○ Episcopalian
- ○ Methodist
- ○ Other Protestant
- ○ Jewish
- ○ Other *Please specify*

INCOME

Q.8 Over the last year, what is the total income of the household your child lives in?

- ○ Less than $9,999
- ○ $10,000 - $19,999
- ○ $20,000 - $39,999
- ○ $40,000 - $59,999
- ○ Over $60,000

OTHER ISSUES

Please rate how concerned you are about the following issues.

	Very concerned	Somewhat concerned	Concerned	Not very concerned	Not at all concerned
R.1 Your child's future health	○	○	○	○	○
R.2 Your child's ability to have children	○	○	○	○	○
R.3 Your child developing cancer	○	○	○	○	○
R.4 Your ability to get health insurance for your child	○	○	○	○	○
R.5 Your ability to get life insurance for your child	○	○	○	○	○
R.6 Any other issues	○	○	○	○	○

Please specify

Please go on to the next page

R.7 For our future planning, what type of information or help do you think should be available to survivors of childhood cancer, leukemia, tumor or similar illness?

Attach additional pages, if necessary.

R.8 Are you planning on moving in the next six months, or do we have your child's correct address?

- ○ Address correct as shown on envelope
- ○ Address correction
- ○ Moving

R.8a Could you please give your new address or location:

Address _____

City _____

State **Zip Code**

- ○ Future address not known

R.9 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 _____

Address _____

City _____

State **Zip Code**

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

Leslie L. Robison, Ph.D.
University of Minnesota
Suite 300
1300 S. Second St.
Minneapolis, MN 55454

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

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