

*Finding cures. Saving children.*



# SJLIFE

## Home Survey

### 5-17 Years of Age Parent Report

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

Parent     Other: \_\_\_\_\_

Today's date:

		/			/				
m	m		d	d		y	y	y	y

**Our mailing address is:**  
St. Jude Children's Research Hospital  
Department of Epidemiology  
Mail Stop 735  
262 Danny Thomas Place  
Memphis, TN 38105-3678

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

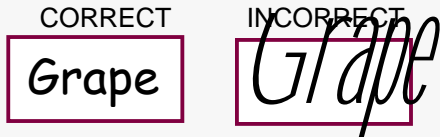
**e-mail:**  
SJLIFE@stjude.org

Please! Do not mark below this line

## 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. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:



### MARKING EXAMPLES

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

#### Example 1

1. During the past month, did your child participate in any physical activities or exercises such as running, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

No     Yes

Not sure		If yes, age at first use	
	Yes		
No			
	<input type="checkbox"/>	<input type="checkbox"/>	[ ] [ ]
	<input checked="" type="checkbox"/>	<input type="checkbox"/>	1 0

#### Example 2

2. Has your child ever taken. . .

- a. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

- b. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Stratterra, Aricept (donepezil), or Provigil (modafinil)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

*ritalin*

#### Example 3

3. When was this condition diagnosed?

04

Month (mm)

2000

Year (yyyy)

Please! Do not mark below this line

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

A1. What is your child's current height without shoes?

--	--	--

Feet      Inches

A2. What is your child's current weight without shoes?

--	--	--

Pounds

## MEDICAL CARE

B1. During the past 2 years, which of the following healthcare providers (excluding dentists) did your child see or talk to for medical care? This includes routine and sick care. *(Mark all that apply)*

- None → Go to Question B4.
- Primary care clinician in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)
- Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)
- Other Medical specialist (e.g., endocrinologist, cardiologist, surgeon)
- Psychiatrist
- Psychologist or counselor
- Physical or occupational therapist
- Other

*If Other, please specify.*

B2. During this 2 year period, how many times did your child see a doctor?

- 0 times → Go to Question B4.
- 1-2 times
- 3-4 times
- 5-6 times
- 7-10 times
- 11-20 times
- More than 20 times

B3. 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 a doctor indicated in question B2 (during the 2 year period) were related to this previous illness?

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

B4. When was your child's most recent routine check-up where a doctor examined and did tests to see if your child had any health problems from cancer or cancer treatment?

- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Never → Go to Question B5, next page.

**B4a. Where was this check-up? (Mark only one)**

- At a cancer survivor clinic
- At a cancer center, but not in a cancer survivor clinic
- At my child's primary care doctor's office
- Other

*If Other, please specify.*

**B4b. At this check-up, did your child's doctor give you or your child advice about what to do to reduce risks or discuss/order medical screening tests?**

- No
- Yes
- Not sure

**B4c. When was the last time that your child had a medical visit with a cancer specialist (oncologist)?**

- 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

**B4d. When was the last time your child had a visit to a special clinic for cancer survivors?**

- Less than 1 year ago
- 1-2 years ago
- More than 2 years but less than 5 years ago
- 5 or more years ago
- Never
- Don't know

**B5. When do you plan to have your child's next visit with a doctor in order to examine him/her for any health problems from cancer or cancer treatment?**

- Less than 1 year from now
- 1-2 years from now
- 3-4 years from now
- 5 or more years from now
- Never
- Don't know

**B6. During the past 12 months, how many times has your child gone to a HOSPITAL EMERGENCY ROOM about his/her own health (This includes emergency room visits that resulted in a hospital admission)?**

--	--

 times

**B7. Does your child currently have a cancer survivorship care plan and/or a summary of treatment for cancer (records from your child's cancer doctor that have details about cancer treatment and medical tests he/she should have to check for future health problems)?**

- No
- Yes
- Not sure

**B8. Does your child's local or primary care doctor have a copy of a cancer survivorship care plan and/or a summary of his/her treatment for cancer?**

- My child does not have a primary care doctor
- My child has a primary care doctor but the doctor does not have a copy of my child's cancer survivorship care plan and/or a summary of my child's treatment for cancer
- Yes
- Not sure

**B9. How often do you or your child carefully check your child's whole body (including the skin on his/her back and back of the legs) for any sign of skin cancer?**

- Once a month
- Every few months
- Every 6 months
- Every year
- Never

**B10. In the past 12 months, has a regular healthcare provider carefully examined your child's whole body for any sign of skin cancer?**

- No
- Yes
- Not sure

## MEDICAL TESTS

**C1. The following questions are about medical screening tests your child may have received.**

**When was the last time your child had . . .**

	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	My child had one, but I don't recall when	I don't know if my child ever had one
a. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a MUGA scan?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. An MRI of his/her heart (he/she was placed inside of a scanner, like a long tube)?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. An MRI of the head or brain?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. A test to measure his/her bone strength or bone mineral density (such as a DEXA scan)?---	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. An ultrasound of the thyroid gland?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. An ultrasound of the carotid arteries (blood vessels in the neck)?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. A skin exam for skin cancer by a healthcare provider?-----	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Continue on next page.*

**C2. Please indicate all medicines/drugs your child took *regularly* during the last two years.**

- We are only asking about medicines/drugs that he/she 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 medicines/drugs that you bought without a prescription (over-the-counter drugs).

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

Not sure  
Yes  
No

If yes, age at first use

years

If yes, is he/she currently taking?

No Yes

2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

4. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

Please! Do not mark below this line

**C2. (Cont.) Please indicate all medicines/drugs your child took *regularly* during the last two years.**

- We are only asking about medicines/drugs that he/she 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 medicines/drugs that you bought without a prescription (over-the-counter drugs).

5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

Not sure		
No	Yes	Yes
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If yes, age at first use

years

--	--

If yes, is he/she currently taking?

Yes	
No	Yes
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

**Please! Do not mark below this line**

**C2. (Cont.) Please indicate all medicines/drugs your child took *regularly* during the last two years.**

- We are only asking about medicines/drugs that he/she 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 medicines/drugs that you bought without a prescription (over-the-counter drugs).

9. 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

10. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Strattera, Aricept (donepezil), or Provigil (modafinil)-----

If yes, specify the name of the drug(s) or indicate you do not know the specific name

11. 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.

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking?
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>



# DENTAL HEALTH

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

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).

In addition to the above instructions, if you answered either "Yes" response to any of the items below, please also mark "Yes" or "No" to whether your child has received this care in the last 2 years.

Has your child ever . . .

		No		Not sure					
						If yes, age at first occurrence	years		
								Has your child received care for this in the <u>last</u> <u>two years</u> ?	
								Yes      No	
D1. Had one or more missing teeth because they did not develop? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D2. Had a lack of or decreased amount of enamel on surface of teeth (hypoplasia)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D3. Had abnormal shaped (small or malformed) teeth? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D4. Had abnormal root development? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D5. Had difficulty in producing saliva (dry mouth) that required treatment such as artificial saliva? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D6. Had severe gingivitis or gum disease requiring surgery or deep cleaning? .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D7. Had root canal therapy? . . . . .	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Not Sure					<input type="checkbox"/>	<input type="checkbox"/>
D8. Had more than 5 cavities? . . . . .	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Not Sure					<input type="checkbox"/>	<input type="checkbox"/>
D9. Lost 6 or more teeth due to decay or gum disease? . . . . .	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Not Sure					<input type="checkbox"/>	<input type="checkbox"/>
D10. Worn a dental bridge (for missing or removed teeth)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D11. Worn removable dentures (complete or partial upper or lower or both)? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D12. Worn a prosthesis to lift his/her palate to improve the quality of his/her voice? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
D13. Had other dental treatment or surgery? . . . . .	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Not Sure					<input type="checkbox"/>	<input type="checkbox"/>
<i>If yes, explain type of procedure.</i>									
D14. Had any other dental problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				<input type="checkbox"/>	<input type="checkbox"/>
<i>If yes, explain type of procedure.</i>									

Please! Do not mark below this line

D15. Has your child ever had dental braces?

- No
- Yes
- Don't know

D16. Does your child currently have dental insurance?

- No
- Yes
- Don't know

D17. Has your child visited the dentist or a dental clinic within the past year for any reason?

- No
- Yes
- Don't know

D18. Has your child had your teeth cleaned by the dentist or dental hygienist within the past year?

- No
- Yes
- Don't know

D19. Does your child have problems finding a dentist to help with his/her dental care because of his/her previous cancer or similar illness?

- No
- Yes
- Don't know

## ALTERNATIVE MEDICINE

E1. In this section, we would like to know about any alternative therapy or complementary healing techniques that your child has used during the last year.

*(Mark all that apply)*

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

*If Other, please specify.*

# MEDICAL CONDITIONS

The next series of questions relate to medical conditions that your child has ever had.

Please indicate, by marking the box (either "No", "Yes", or "Not sure") if a doctor or other health care professional has told you that your child has or has had any of the following conditions. If you answer "yes", please give your child's age when the condition first occurred.

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).**

## HEARING/VISION/SPEECH

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
F1. Hearing loss requiring a hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F2. Deafness in both ears not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F3. Deafness in only one ear not completely corrected by hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F4. Tinnitus or ringing in the ears? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F5. Persistent dizziness or vertigo? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F6. Hearing loss, not requiring a hearing aid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F7. Any other hearing problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, describe the other hearing problem(s). List the age at first occurrence for each problem separately.**

F8. Legally blind in only one eye? . . . . .

**If yes, does he/she have any sight in this eye?**  
 No  Yes

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
F9. Legally blind in both eyes? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
<b>If yes, does he/she have any sight?</b> <input type="checkbox"/> No <input type="checkbox"/> Yes					
F10. Cataracts? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F11. Glaucoma (excess pressure in the eyeball)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F12. Problems with double vision? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F13. A detached retina or any other condition of the retina? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, describe the other condition(s). List the age at first occurrence for each condition separately.**

F14. Crossed or turned eyes (strabismus)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F15. Lazy eye (amblyopia)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F16. Any other trouble seeing with one or both eyes even when wearing glasses? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F17. Very dry eyes requiring eye drops or ointment? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F18. Any other eye problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

**If yes, describe the other eye problem(s). List the age at first occurrence for each problem separately.**

Please! Do not mark below this line

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.

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
F19. Stammering or stuttering speech? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F20. Any other speech defects? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe the other speech defect(s). List the age at first occurrence for each defect separately.*

F21. Abnormal sense of taste? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F22. Loss of taste lasting for 3 months or more? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
F23. Loss of smell lasting for 3 months or more? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

## URINARY SYSTEM

G1. Kidney stones? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G2. REPEATED kidney or bladder infections (more than 3 in any 12 month period)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G3. Dialysis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G4. Blood in his/her urine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G5. Protein in his/her urine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G6. Urinary incontinence? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
G7. Any other kind of kidney, bladder or urinary tract disorder? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe the other disorder(s). List the age at first occurrence for each disorder separately.*

## HEART AND CIRCULATORY SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	Yes, but the condition is no longer present	Yes, and the condition is still present	No	Not sure	If yes, age at first occurrence years
H1. Congestive heart failure or cardiomyopathy (weak heart muscle)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H2. A myocardial infarction (heart attack)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H4. Coronary heart disease? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, describe the type of problem(s). List the age at first occurrence for each problem separately.*

H5. Hypertension (high blood pressure) requiring medication? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	----------------------

*If yes, does he/she currently take hypertension medication?*

No  Yes

H6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H7. Pericarditis or fluid around the heart? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H8. Pericardial constriction (scarring or tightness of the sac around the heart)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H9. Stiff or leaking heart valves? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H10. Blood clot in head, lung, arm, leg, or pelvis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
H11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
H12. High cholesterol (or triglyceride) requiring prescription medication? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**If yes, does he/she currently take medication for this?**  
 No  Yes

H13. Any other heart or circulatory problems? . . . . .

H14. Has anyone in your child's immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?

No

## HORMONAL SYSTEMS

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
11. An overactive thyroid gland (hyperthyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
12. An underactive thyroid gland (hypothyroid)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
13. Thyroid nodules? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
14. Swollen or enlarged thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
15. Diabetes that can be controlled with diet? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
16. Diabetes controlled with pills or tablets? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
17. Diabetes controlled with insulin shots? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
18. Deficiency of growth hormone? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
19. Has your child received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**If yes, does he/she currently take injections of growth hormone?**  
 No  Yes

I10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)? . . . . .

I11. Has your child ever broken a bone? . . . . .

**If yes, describe all occurrences of broken bones. List the age for each individual occurrence.**

I12. Any other hormonal problems? . . . . .

**If yes, describe the other hormonal problem(s). List the age at first occurrence for each problem separately.**

Please! Do not mark below this line

**Males** → Go to Question J1.

113. **FEMALES** - Has your child had a menstrual period naturally, that is, without needing hormones or medication?

No  Yes

If yes, age at first occurrence:

If No, → Go to Question I15.

114. **FEMALES** - At what age did your child last have a menstrual period naturally, without needing hormones or medication?

years and   months old

115. **FEMALES** - Which one of the following statements best describes your child? (Select only one)

- a. She is having regular periods and she is not taking birth control pills or female hormones (example: Premarin, estrogen)
- b. She is having regular periods but she is using birth control pills to prevent a pregnancy
- c. Her menstrual periods are irregular and she is taking birth control pills or female hormones to regulate her periods
- d. Her menstrual periods are irregular but she is not using birth control pills or female hormones to regulate her periods
- e. She is currently pregnant
- f. She is not having menstrual periods naturally but she is taking birth control pills or female hormones
- g. She is not having menstrual periods naturally and she is not taking birth control pills or female hormones
- h. Other

If Other, please describe.

If you selected a, b, c, d, or e → Go to Question J1.

If you selected f, g, or h → Go to Question I16.

116. **FEMALES** - What caused your child's menstrual periods to stop? (Select only one)

- Normal or early menopause
- Surgery (example: a hysterectomy)
- Pregnancy
- Don't know
- Other

If Other, please describe.

## RESPIRATORY SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	Yes, but the condition is no longer present				No	Yes, and the condition is still present	If yes, age at first occurrence
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
						years	
J1. Asthma? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J2. Chronic cough or shortness of breath for more than one month? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J3. Has your child had a need for extra oxygen? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J4. Pneumonia, 3 or more times in the past 2 years? . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J5. Emphysema or other chronic obstructive pulmonary disease (COPD)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J6. Lung fibrosis or "scarring" of the lung? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J7. Problems with breathing while at rest that lasted for more than 3 months? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	
J8. Any other breathing or lung problems? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>	

If yes, describe the other problem(s). List the age at first occurrence for each problem separately.

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.

## DIGESTIVE SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence years
K1. Hepatitis? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, what type(s)? (Mark all that apply)</b>					
<input type="checkbox"/> Hepatitis A					
<input type="checkbox"/> Hepatitis B					
<input type="checkbox"/> Hepatitis C					
<input type="checkbox"/> Don't know					
<input type="checkbox"/> Other					
K2. Cirrhosis of the liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K3. Fatty liver? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K4. Any other liver trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
<b>If yes, describe the other liver problem(s). List the age at first occurrence for each problem separately.</b>					
K5. Intestinal (colon) polyps? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K6. Esophageal strictures (narrowing of the esophagus)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K7. Rectal or anal fistula? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K8. Rectal or anal stricture (narrowing or scarring)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K9. Stricture (narrowing or scarring) of the small or large intestine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
K10. Any other stomach or digestive trouble? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**If yes, describe the other problem(s). List the age at first occurrence for each problem separately.**

## SURGICAL PROCEDURES

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

	No	Yes	Not sure	If yes, age at first occurrence years
L1. Amputation of an arm, leg, hand, foot? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**If yes, specify (example: left hand, right foot). List the age for each amputation separately.**

L2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
L3. Other surgery of spinal cord or spine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**If yes, specify all surgeries of the spinal cord or spine. List the age at which each surgery occurred.**

L4. Leg lengthening or shortening procedures? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>
L5. Joint replacement? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/> <input type="text"/>

**If yes, specify all joint replacements. List the age at which each joint replacement occurred.**

Please! Do not mark below this line

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

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

	No	Yes	Not sure	If yes, age at first occurrence years
--	----	-----	----------	--

L6. Other bone surgery? . . . . .

*If yes, specify all other bone surgeries. List the age at which each bone surgery occurred.*

L7. Coronary artery bypass surgery? . . . . .

L8. Pericardiectomy (stripping of the sac around the heart)? . . . . .

L9. Heart catheterization ("heart cath")? . . . . .

L10. Angioplasty (enlarging a heart vessel using a balloon) or stent placement to keep vessel open? . . . . .

L11. Surgery for heart valve replacement? . . . . .

L12. Surgery for pacemaker? . . . . .

L13. Other heart surgery? . . . . .

*If yes, specify all other heart surgeries. List the age at which each heart surgery occurred.*

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

	No	Yes	Not sure	If yes, age at first occurrence years
L14. Surgery to repair a fistula (an abnormal connection between the intestine or rectum and other structures)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L15. Surgery for intestinal obstruction (blocked intestines)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L16. Colostomy or ileostomy (stool going into a bag)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L17. Removal of part or all of the colon . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L18. Removal of part or all of the rectum. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L19. Biopsy or removal of lump in thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L20. Removal of part or all of the thyroid gland? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L21. Removal of the spleen? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L22. Bladder, ureter, or kidney surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L23. Removal of all or part of a kidney? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L24. Liver or gall bladder surgery? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L25. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L26. Breast biopsy? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L27. Breast-conserving or breast-sparing surgery (lumpectomy)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
L28. Mastectomy or removal of a breast? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

*If yes, was one or both breasts removed?*

Left only     Right only     Both

Please! Do not mark below this line



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

	No	Yes	Not sure	If yes, age at first occurrence
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/>

L29. Any lung surgery? . . . . .

*If yes, specify all lung surgeries. List the age at which each lung surgery occurred.*

L30. Periodontal (gum) surgery? . . . . .

L31. Heart transplant? . . . . .

L32. Lung transplant? . . . . .

L33. Kidney transplant? . . . . .

L34. Liver transplant? . . . . .

L35. Bone marrow transplant? . . . . .

L36. Other organ transplant? . . . . .

*If yes, specify all other organ transplants. List the age for each individual transplant.*

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

	No	Yes	Not sure	If yes, age at first occurrence
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/>

L37. Cataract surgery? . . . . .

**Males** → Go to Question L42.

L38. Removal of one ovary? . . . . .

L39. Removal of both ovaries? . . . . .

L40. Removal of uterus? . . . . .

L41. Surgery of the vagina? . . . . .

**Females** → Go to Question L45.

L42. Removal of one testis? . . . . .

L43. Removal of both testes? . . . . .

L44. Removal of part or all of the prostate gland (prostatectomy) . . . . .

L45. Any other surgery? . . . . .

*If yes, specify all other surgeries. List the age at which each other surgery occurred.*

Please! Do not mark below this line

# BRAIN AND NERVOUS SYSTEM

Have you ever been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
M1. Problems with learning or memory? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**If yes and still present**, please rate the severity of these problems:

- Mild**; does not interfere with work, school, or general life. My child does/did need special help in school.
- Moderate**; interferes with work, school, or general life, but my child is capable of independent living. My child uses/used special help in school.
- Severe**; My child is significantly impaired in his/her school or work performance or in general life.
- Disabling**; My child is unable to perform daily activities such as taking care of himself/herself; My child requires full-time help or is living in an institution for people with disabling conditions.

M2. Epilepsy, repeated seizures, convulsions, or blackouts? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
---	--------------------------	--------------------------	--------------------------	--------------------------	---

**If yes, describe this problem(s). List the age at first occurrence for each problem separately.**

**If yes**, is your child currently taking medication for this?

- No  Yes

**If yes**, name of medications

Date of last seizure

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
M	M		D	D		Y	Y	Y	Y

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
M3. Migraine? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
M4. Other severe headaches? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
M5. Other repeated headaches? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**If yes, list medications required to control migraine or other severe headaches.**

M6. Problems with balance, equilibrium, or ability to reach for or manipulate objects? . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	---

**If yes and still present**, please rate the severity of these problems:

- Mild**; does not affect walking or daily routine.
- Moderate**; it is bothersome and affects walking but my child is able to do daily routine.
- Severe**; this problem significantly affects walking and daily routine.
- Disabling**; My child requires a wheelchair or cannot walk because of this problem.

M7. Tremors or problems with movements? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
---	--------------------------	--------------------------	--------------------------	--------------------------	---

M8. Problems chewing or swallowing solids or liquids? .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
---	--------------------------	--------------------------	--------------------------	--------------------------	---

M9. Decreased sense of touch or feeling in hands, fingers, arms or legs? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	---

M10. Prolonged pain in arms or legs. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	---

M11. Prolonged pain in back . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
---------------------------------------	--------------------------	--------------------------	--------------------------	--------------------------	---

M12. Abnormal sensation in arms, legs or back? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	---

M13. Weakness or inability to move arm(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
--	--------------------------	--------------------------	--------------------------	--------------------------	---

Have you **ever** been told by a doctor or other health care professional that your child has, or has had. . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence
M14. Weakness or inability to move leg(s)? . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>
M15. Paralysis of any kind?. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	years <input type="text"/> <input type="text"/>

**If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.**

M16. Stroke? . . . . .     years

**If no → Go to M18.**

**If yes, as a result of the stroke . . .**

a. Did the symptoms last more than 24 hours?  
 No  Yes

**Did the stroke affect:**

b. Speech. . . . .

c. Balance and coordination.      
 Only one side of the body .      
 Both sides of the body . . .

d. Did your child lose consciousness?  
 No  Yes

e. Did your child experience sensory loss (vision, taste, smell)? . . . . .      
 Only one side of the body .      
 Both sides of the body . . .

f. Did your child have weakness or inability to move arm(s)? . . . . .      
 Only one side of the body .      
 Both sides of the body . . .

g. Did your child have weakness or inability to move leg(s)? . . . . .      
 Only one side of the body .      
 Both sides of the body . . .

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure
h. Did your child have paralysis of any kind? . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Only one side of the body .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Both sides of the body . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**If yes, describe the paralysis. List the age at first occurrence for each episode of paralysis separately.**

M17. In your child's lifetime, how many strokes has your child had . . . . .

years

M18. Any other brain or nervous system problems? . . . . .     years

**If yes, describe the other problem(s). List the age at first occurrence for each problem separately.**

M19. Does your child have any driving restrictions because of brain or nervous system problems (such as seizures)?

No

Yes, but my child is able to drive

Yes, my child is unable to drive

Unsure, my child does not drive

M20. Does your child have any work restrictions because of brain or nervous system problems (such as seizures)?

No

Yes, but my child is able to work

Yes, my child is unable to work

Unsure, my child does not work

Please! Do not mark below this line

# HEALTH HABITS

## Smoking

The following questions are referring to cigarettes containing tobacco.

**N1. Has your child smoked at least 100 cigarettes in his/her lifetime?**

No → **Go to Question N3.**

Yes ↓

**N2. Does your child smoke cigarettes now?**

No

Yes

**N3. To your knowledge, has your child ever used any of these products? (Mark all that apply)**

	Never used	No longer use	Occasionally use	Regularly use
Chewing tobacco .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Snuff tobacco .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pipes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cigars .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-cigarettes .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Human papillomavirus vaccination

**N4. FEMALES 9 OR OLDER-** The human papillomavirus (HPV) vaccine is given to prevent cervical cancer in girls and women. The HPV vaccine is sometimes called the HPV shot, Cervarix, or Gardasil. Has your child ever received one or more doses of the HPV vaccine?

Yes

No → **Go to Question N6.**

Don't Know → **Go to Question N6.**

**N4a. How old was your child when she received the first dose of the HPV vaccine? .....**

**N4b. How many shots of the HPV vaccine did your child receive?**

1 shot    2 shots    3 shots    Don't Know

**N5. MALES 9 OR OLDER-** The human papillomavirus (HPV) vaccine is given to prevent HPV infection and genital warts in boys and men. The HPV vaccine is sometimes called the HPV shot, Cervarix, or Gardasil. Has your child ever received one or more doses of the HPV vaccine?

Yes

No → **Go to Question N6.**

Don't Know → **Go to Question N6.**

**N5a. How old was your child when he received the first dose of the HPV vaccine? .....**

**N5b. How many shots of the HPV vaccine did your child receive?**

1 shot

2 shots

3 shots

Don't Know

## Influenza vaccination

**N6. During the past 12 months, has your child had either a flu shot or a flu vaccine that was sprayed in his/her nose?**

Yes

No

Don't Know

**N7. A pneumonia shot or pneumococcal vaccine is usually given only once or twice in a person's lifetime and is different from the flu shot. Has your child ever had a pneumonia shot?**

Yes

No

Don't Know

# CANCER, LEUKEMIA, OR TUMOR

**O1. At any time following your child's original diagnosis, was he/she diagnosed with another cancer, leukemia, tumor, or similar illness? (Include any relapse or recurrence of the original diagnosis).**

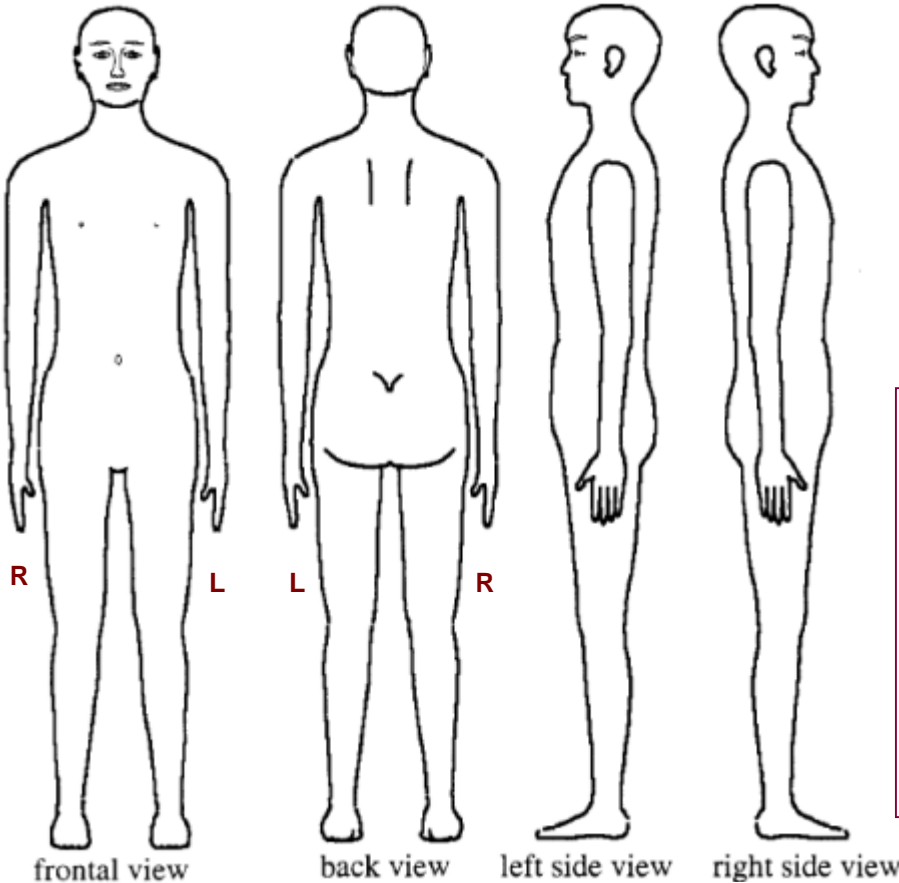
No → **Go to Question P1, page 23.**

Yes ↴

**O2. What was the name of this disease?**

**O3. Where was it located? (Example: right upper arm, left ear)**

If the condition in item O2 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your child's cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.



**O4. Did you have treatment for this disease?**

No → **Skip O4a and go to Question O5.**

Yes → **O4a. What treatments did you receive? (Mark all that apply)**

- Chemotherapy
- Radiation therapy
- Surgery

**O5. Where was this diagnosed?**

Doctor's name
Hospital or clinic
Address
City, State, Zip code

**O6. Was this a:**

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

**Date of Recurrence or New Diagnosis:**

--	--	--	--	--	--

Month (mm)      Year (yyyy)

**O7. Has your child had any additional cancers, leukemias, tumors, or similar illnesses after this second one?**

No → **Go to Question P1, next page.**

Yes ↓

**O8. What was the name of this disease?**

**O9. Where was it located? (Example: right upper arm, left ear)**

**O10. Did you have treatment for this disease?**

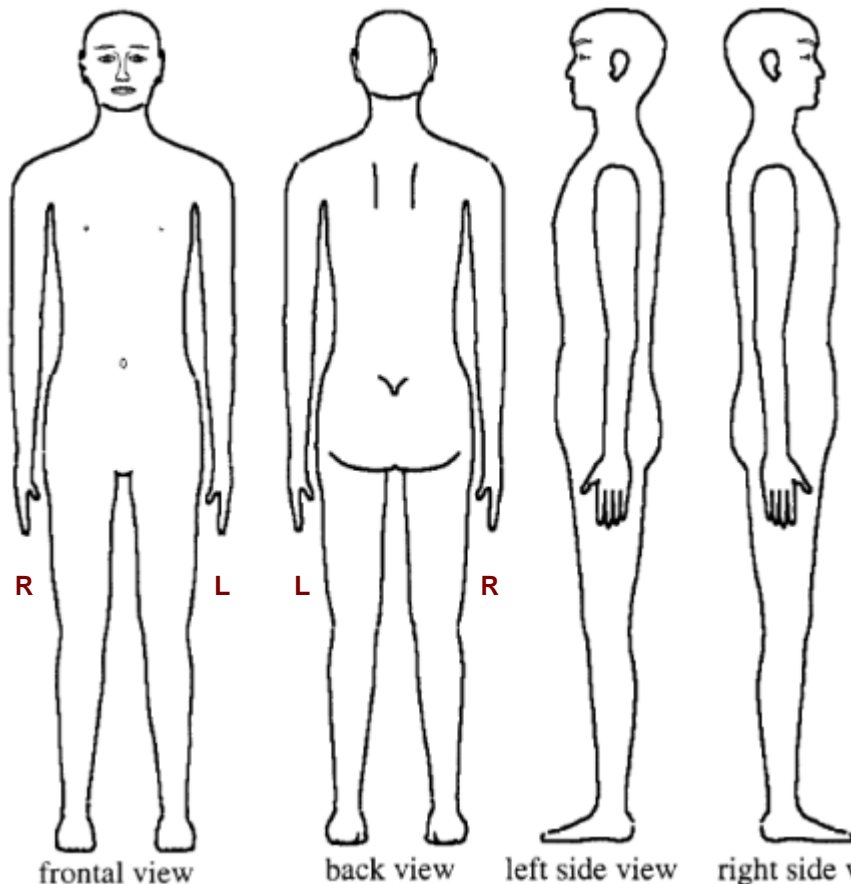
No →

Yes → **O10a. What treatments did you receive? (Mark all that apply)**

- Chemotherapy
- Radiation therapy
- Surgery

**O11. Where was this diagnosed?**

If the condition in item O7 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your child's cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.



**O12. Was this a:**

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

**Date of Recurrence or New Diagnosis:**

--	--	--	--	--	--

Month (mm)      Year (yyyy)

**Please use a separate sheet of paper for additional cancers**

# HOSPITALIZATIONS

We are interested in any admissions to the hospital for illness, surgical, or diagnostic procedures, including psychiatric/mental health hospitalization or short stays of 24 hours or less that your child may have had in the last 12 months. **DO NOT INCLUDE PREGNANCY RELATED ADMISSIONS** or **EMERGENCY ROOM VISITS**.

P1. Has your child been admitted to a hospital in the last 12 months?

- No → Go to Section Q, next page.  
 Yes

P2. How many times has your child been admitted to a hospital in the last 12 months?

P3. What was the reason for the first hospitalization?

P3a. What procedures/surgeries were performed?

P3b. Where was your child hospitalized?

Hospital
Address
City, State, Zip code
Doctor's name

P3c. Date of first hospitalization:

Month (mm)			Year (yyyy)			

P4. What was the reason for the second hospitalization?

P4a. What procedures/surgeries were performed?

P4b. Where was your child hospitalized?

Hospital
Address
City, State, Zip code
Doctor's name

P4c. Date of second hospitalization:

Month (mm)			Year (yyyy)			

**Please use a separate sheet of paper for additional hospitalizations**

# PREGNANCY AND OFFSPRING

## Female

Q1. Has your child ever had any pregnancies?

No → Go to page R1a, next page.

Yes └

Q2. Is your daughter currently pregnant?

No

Yes

Continue to Question Q5 below.

## Male

Q3. Has a woman ever been pregnant by your child?

No → Go to page R1a, next page.

Yes └

Q4. Is she currently pregnant?

No

Yes

Continue to Question Q5 below.

Q5. Please fill in the following information for each of your child's pregnancies, or each time a woman has become pregnant by your child, regardless of the outcome.

### Pregnancy outcome

	Live birth	Stillbirth	Miscarriage	Medical abortion	Currently pregnant	Your child's age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
Pregnancy 1. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 2. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 3. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 4. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Pregnancy 5. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Please! Do not mark below this line



# GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions that your child has. Indicate "Yes" only if a physician has told you that your child was born with, or has the condition.

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 your child has never had that condition. If you have never heard of these conditions, it is unlikely that your child has had them.

**R1a. Have you ever been told by a doctor that your child has...**

	No	Yes	Not sure
a. Ataxia telangiectasia . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Beckwith-Wiedemann syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2) . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Bloom's syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Down syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Klinefelter's syndrome. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Fanconi's anemia. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Multiple exostoses . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Familial adenomatous polyposis (FAP or Gardner syndrome). . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Neurofibromatosis (Type 1). . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Nevoid basal cell carcinoma syndrome . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Turner's syndrome. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. Von Hippel-Lindau syndrome. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Wiskott-Aldrich syndrome. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Xeroderma pigmentosum. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Polycystic kidney disease. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q. WAGR syndrome. . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r. Li-Fraumeni syndrome (p53 gene abnormality). . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
s. Any other genetic disorder . . . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If yes, describe this disorder.*

**R1b. Has anyone in your child's immediate family (blood relatives only) ever had any of the conditions in Question R1a? (Mark all that apply)**

My child's . . .	What conditions?
<input type="checkbox"/> Mother →	
<input type="checkbox"/> Father →	
<input type="checkbox"/> Full brother →	
<input type="checkbox"/> Full sister →	
<input type="checkbox"/> Son →	
<input type="checkbox"/> Daughter →	

## CONDITIONS PRESENT AT BIRTH

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

**R2. Has your child ever had genetic counseling for cancer risk?**

- No
- Yes

*Continue on next page.*

**R3a. To the best of your knowledge, was your child born with...**

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

*If other, please specify.*

m. Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. Any kidney, bladder, or genital abnormalities.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o. Undescended testes (males only).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p. Any other birth defects .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*If other, please specify.*

**R3b. Has anyone in your child's immediate family (blood relatives only) ever had any of the conditions in Question R3a? (Mark all that apply)**

My child's ...	What conditions?
<input type="checkbox"/> Mother →	
<input type="checkbox"/> Father →	
<input type="checkbox"/> Full brother →	
<input type="checkbox"/> Full sister →	
<input type="checkbox"/> Son →	
<input type="checkbox"/> Daughter →	

**R4. Has anyone in your child's immediate family (blood relatives only) ever had cancer? (Mark all that apply)**

My child's ...	What types?
<input type="checkbox"/> Mother →	
<input type="checkbox"/> Father →	
<input type="checkbox"/> Full brother →	
<input type="checkbox"/> Full sister →	
<input type="checkbox"/> Son →	
<input type="checkbox"/> Daughter →	

Please! Do not mark below this line

# CONTACT INFORMATION

1. Does your child use a cell phone?

Yes  No **→ Go to question 3.**

2. Does your child use a "smartphone" that can access the internet or download "apps" (e.g. iPhone, Android, Blackberry, Windows)?

Yes  No

3. Which of the following types of devices does your child use to access the internet?

**(Mark all that apply)**

Computer or laptop

Tablet (iPad or similar)

Smartphone

Other, specify: \_\_\_\_\_

My child does not access the internet

Do you have an email address we could use to contact you?  No  Yes →  
This will not be shared with individuals outside of St. Jude.

Your Email Address:

**We have your current address and phone as: THE PARENTS OF**

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

Correct  Not correct  Moving

If this information is not correct, please give us your correct address or location:


Address:			
City:		State:	
Zip code:	Cell phone:	Home phone:	Work phone:

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	
City:		State:	
Zip code:	Cell phone:	Home phone:	Work phone:

Please! Do not mark below this line

**We are always interested in your input in the St. Jude Life study.  
Use this space for any additional comments you may have:**



---

Please! Do not mark below this line