St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

SJLIFE

Home Survey
5-17 Years of Age Parent Report

Control

Finding cures. Saving children.

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:
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Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

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1-800-775-2167

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Please! Do not mark below this line

Survey #255

1280281204

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:

CORRECT

Grape

INCORRECT

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

Example 2

2. Has your child ever taken. . .

	No	Yes	Not sure	If yes, age at first use
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)	X	☐	☐	
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, Strattera, Aricept (donepezil), or Provigil (modafinil)		☒	☐	10
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?

0	4	2	0	0	0

Month (mm) Year (yyyy)

Please! Do not mark below this line

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. If your child was ever 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?

- ☐ No history of cancer
- ☐ 0 visits
- ☐ 1-2 visits
- ☐ 3-4 visits
- ☐ 5-6 visits
- ☐ 7-10 visits
- ☐ 11-20 visits
- ☐ More than 20 visits

B4. When do you plan to have your child's next visit with a doctor in order to examine him/her for any health problems?

- ☐ 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

Please! Do not mark below this line

B5. 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

B6. 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

B7. 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

Continue on next page.

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?	☐	☐	☐	☐	☐	☐	☐
b. An MRI of his/her heart (he/she was placed inside of a scanner, like a long tube)?	☐	☐	☐	☐	☐	☐	☐
c. An MRI of the head or brain?	☐	☐	☐	☐	☐	☐	☐
d. A test to measure his/her bone strength or bone mineral density (such as a DEXA scan)?	☐	☐	☐	☐	☐	☐	☐
e. An ultrasound of the thyroid gland?	☐	☐	☐	☐	☐	☐	☐
f. An ultrasound of the carotid arteries (blood vessels in the neck)?	☐	☐	☐	☐	☐	☐	☐
g. A skin exam for skin cancer by a healthcare provider?	☐	☐	☐	☐	☐	☐	☐

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).**

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking? No	If yes, is he/she currently taking? Yes
1. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil----------	☐	☐	☐	years ☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, 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).**

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking? No	If yes, is he/she currently taking? Yes
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----------	☐	☐	☐	☐☐ years	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
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).**

	No	Yes	Not sure	If yes, age at first use	If yes, is he/she currently taking? No	If yes, is he/she currently taking? Yes
9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil----------	☐	☐	☐	years ☐☐	☐	☐
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.						

Please! Do not mark below this line

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

If yes, explain type of procedure.

D14. Had any other dental problems?	☐	☐	☐	☐		☐	☐

If yes, explain type of procedure.

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

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	☐	☐	☐
b. Biofeedback	☐	☐	☐
c. Chiropractor	☐	☐	☐
d. Crystals/magnets	☐	☐	☐
e. Nutritional supplements (such as Omega-3 fatty acids)	☐	☐	☐
f. Herbal remedies (such as St. John's Wort, Echinacea)	☐	☐	☐
g. Homeopathic remedies	☐	☐	☐
h. Hypnosis/guided imagery	☐	☐	☐
i. Massage/body work	☐	☐	☐
j. Meditation/relaxation	☐	☐	☐
k. Modified diet (gluten-free, vegan)	☐	☐	☐
l. Naturopathic treatments	☐	☐	☐
m. Spiritual healing/prayer	☐	☐	☐
n. Therapeutic touch	☐	☐	☐
o. Vitamins/minerals (not regular multi-vitamin, but high dose C, zinc, etc.)	☐	☐	☐
p. Yoga/Tai Chi/Qi Gong/special exercise	☐	☐	☐
q. Other	☐	☐	☐

If Other, please specify.

Please! Do not mark below this line

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

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

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
F9. Legally blind in both eyes?	☐	☐	☐	☐	☐☐

If yes, does he/she have any sight?
☐ No ☐ Yes

F10. Cataracts?	☐	☐	☐	☐	☐☐
F11. Glaucoma (excess pressure in the eyeball)?	☐	☐	☐	☐	☐☐
F12. Problems with double vision?	☐	☐	☐	☐	☐☐
F13. A detached retina or any other condition of the retina?	☐	☐	☐	☐	☐☐

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

F14. Crossed or turned eyes (strabismus)?	☐	☐	☐	☐	☐☐
F15. Lazy eye (amblyopia)?	☐	☐	☐	☐	☐☐
F16. Any other trouble seeing with one or both eyes even when wearing glasses?	☐	☐	☐	☐	☐☐
F17. Very dry eyes requiring eye drops or ointment?	☐	☐	☐	☐	☐☐
F18. Any other eye problems?	☐	☐	☐	☐	☐☐

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. . .

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
F19. Stammering or stuttering speech?	☐	☐	☐	☐	
F20. Any other speech defects?	☐	☐	☐	☐	

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

F21. Abnormal sense of taste?	☐	☐	☐	☐	
F22. Loss of taste lasting for 3 months or more?	☐	☐	☐	☐	
F23. Loss of smell lasting for 3 months or more?	☐	☐	☐	☐	

URINARY SYSTEM

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

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. . .

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	If yes, age at first occurrence (years)
H1. Congestive heart failure or cardiomyopathy (weak heart muscle)?	☐	☐	☐	
H2. A myocardial infarction (heart attack)?	☐	☐	☐	
H3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor?	☐	☐	☐	
H4. Coronary heart disease?	☐	☐	☐	

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?	☐	☐	☐	
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)?	☐	☐	☐	
H7. Pericarditis or fluid around the heart?	☐	☐	☐	
H8. Pericardial constriction (scarring or tightness of the sac around the heart)?	☐	☐	☐	
H9. Stiff or leaking heart valves?	☐	☐	☐	
H10. Blood clot in head, lung, arm, leg, or pelvis?	☐	☐	☐	
H11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat?	☐	☐	☐	

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 (years)
H12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	☐☐
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, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
I1. An overactive thyroid gland (hyperthyroid)?	☐	☐	☐	☐	☐☐
I2. An underactive thyroid gland (hypothyroid)?	☐	☐	☐	☐	☐☐
I3. Thyroid nodules?	☐	☐	☐	☐	☐☐
I4. Swollen or enlarged thyroid gland?	☐	☐	☐	☐	☐☐

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 (years)
I5. Diabetes that can be controlled with diet?	☐	☐	☐	☐	☐☐
I6. Diabetes controlled with pills or tablets?	☐	☐	☐	☐	☐☐
I7. Diabetes controlled with insulin shots?	☐	☐	☐	☐	☐☐
I8. Deficiency of growth hormone?	☐	☐	☐	☐	☐☐
I9. Has your child received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?	☐	☐	☐	☐	☐☐
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.

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence (years)
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.

I13. **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.

I14. **FEMALES** - At what age did your child last have a menstrual period naturally, without needing hormones or medication?

☐☐ **years and** ☐☐ **months old**

I15. **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.

I16. **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. . .

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

If yes, describe the other 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.

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?	☐	☐	☐	☐	

If yes, what type(s)? ***(Mark all that apply)***

- ☐ Hepatitis A
- ☐ Hepatitis B
- ☐ Hepatitis C
- ☐ Don't know
- ☐ Other

K2. Cirrhosis of the liver?	☐	☐	☐	☐	
K3. Fatty liver?	☐	☐	☐	☐	
K4. Any other liver trouble?	☐	☐	☐	☐	

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

K5. Intestinal (colon) polyps?	☐	☐	☐	☐	
K6. Esophageal strictures (narrowing of the esophagus)?	☐	☐	☐	☐	
K7. Rectal or anal fistula?	☐	☐	☐	☐	
K8. Rectal or anal stricture (narrowing or scarring)?	☐	☐	☐	☐	
K9. Stricture (narrowing or scarring) of the small or large intestine?	☐	☐	☐	☐	
K10. Any other stomach or digestive trouble?	☐	☐	☐	☐	

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?	☐	☐	☐	

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)?	☐	☐	☐	
L3. Other surgery of spinal cord or spine?	☐	☐	☐	

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?	☐	☐	☐	
L5. Joint replacement?	☐	☐	☐	

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.

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

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 (years)
L29. Any lung surgery?	☐	☐	☐	☐☐

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

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

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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 (years)
M1. Problems with learning or memory?	☐	☐	☐	☐	

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?	☐	☐	☐	☐	

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
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 (years)
M3. Migraine?	☐	☐	☐	☐	
M4. Other severe headaches?	☐	☐	☐	☐	
M5. Other repeated headaches?	☐	☐	☐	☐	

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?	☐	☐	☐	☐	

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?	☐	☐	☐	☐	
M8. Problems chewing or swallowing solids or liquids?	☐	☐	☐	☐	
M9. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
M10. Prolonged pain in arms or legs.	☐	☐	☐	☐	
M11. Prolonged pain in back	☐	☐	☐	☐	
M12. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
M13. Weakness or inability to move arm(s)?	☐	☐	☐	☐	

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
M14. Weakness or inability to move leg(s)?	☐	☐	☐	☐	years ☐☐
M15. Paralysis of any kind?.	☐	☐	☐	☐	

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

M16. Stroke?.	☐	☐	☐	☐	☐☐

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, and the condition is still present	Yes, but the condition is no longer present	Not sure
h. Did your child have paralysis of any kind?. . . .	☐	☐	☐	☐
Only one side of the body .	☐	☐	☐	☐
Both sides of the body . . .	☐	☐	☐	☐

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 . . . . . ☐☐

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	☐	☐	☐	☐
Snuff tobacco	☐	☐	☐	☐
Pipes	☐	☐	☐	☐
Cigars	☐	☐	☐	☐
E-cigarettes	☐	☐	☐	☐

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

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMOR

O1. At any time was your child diagnosed with cancer, leukemia, tumor, or similar illness?

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

☐ Yes

O2. What was the name of this disease?

O3. Did he/she have treatment for this disease?

☐ No → *Skip O3a and go to Question P1, next page.*

☐ Yes → **O3a. What treatments did he/she receive?** ***(Mark all that apply)***

☐ Chemotherapy

☐ Radiation therapy

☐ Surgery

Continue on next page.

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

Please! Do not mark below this line

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.	☐	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 2.	☐	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 3.	☐	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 4.	☐	☐	☐	☐	☐	☐☐	☐☐	☐☐
Pregnancy 5.	☐	☐	☐	☐	☐	☐☐	☐☐	☐☐

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	☐	☐	☐
b. Beckwith-Wiedemann syndrome	☐	☐	☐
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2)	☐	☐	☐
d. Bloom's syndrome	☐	☐	☐
e. Down syndrome	☐	☐	☐
f. Klinefelter's syndrome	☐	☐	☐
g. Fanconi's anemia	☐	☐	☐
h. Multiple exostoses	☐	☐	☐
i. Familial adenomatous polyposis (FAP or Gardner syndrome)	☐	☐	☐
j. Neurofibromatosis (Type 1)	☐	☐	☐
k. Nevoid basal cell carcinoma syndrome	☐	☐	☐
l. Turner's syndrome	☐	☐	☐
m. Von Hippel-Lindau syndrome	☐	☐	☐
n. Wiskott-Aldrich syndrome	☐	☐	☐
o. Xeroderma pigmentosum	☐	☐	☐
p. Polycystic kidney disease	☐	☐	☐
q. WAGR syndrome	☐	☐	☐
r. Li-Fraumeni syndrome (p53 gene abnormality)	☐	☐	☐
s. Any other genetic disorder	☐	☐	☐

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?***
☐ Mother →	
☐ Father →	
☐ Full brother →	
☐ Full sister →	
☐ Son →	
☐ 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	☐	☐	☐
b. Club foot	☐	☐	☐
c. Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime)	☐	☐	☐
d. Deafness or impaired hearing at birth	☐	☐	☐
e. Blindness or difficulty seeing at birth	☐	☐	☐
f. Eyes different colors or missing an iris (the colored part of the eye)	☐	☐	☐
g. Hydrocephalus (excessive water around or within the brain)	☐	☐	☐
h. Spina bifida or other neural tube defect	☐	☐	☐
i. Unusually small head (microcephaly)	☐	☐	☐
j. Unequal sized limbs (hemihypertrophy)	☐	☐	☐
k. Extra fingers, deformed chest, shortened limbs or any other skeletal abnormality	☐	☐	☐
l. Hole in the heart or other congenital heart defect	☐	☐	☐

If other, please specify.

m. Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines)	☐	☐	☐
n. Any kidney, bladder, or genital abnormalities	☐	☐	☐
o. Undescended testes (males only)	☐	☐	☐
p. Any other birth defects	☐	☐	☐

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?***
☐ Mother →	
☐ Father →	
☐ Full brother →	
☐ Full sister →	
☐ Son →	
☐ 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?***
☐ Mother →	
☐ Father →	
☐ Full brother →	
☐ Full sister →	
☐ Son →	
☐ 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

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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

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