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:

Name

Person completing this questionnaire is:

percomp text

Your relationship:

2 ☐ Parent 3 ☐ Other: percode coded _____

relation

Today's date: m m / d d / y y y y

datecomp

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

SJLIFEID

Please! Do not mark below this line

MRN

3774120105

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. Do not use a felt-tip or roller-ball pen. These may cause smudging.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:

CORRECT INCORRECT

MARKING EXAMPLES

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

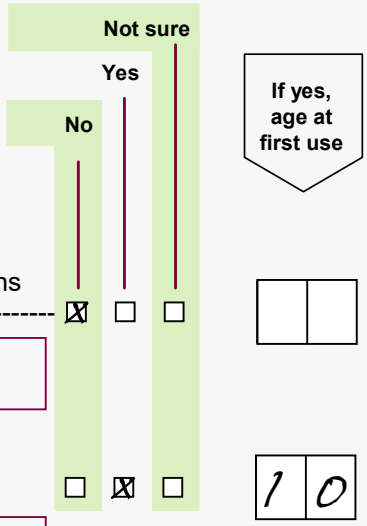
Example 1

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. . .



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, 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?

04 Month (mm) 2000 Year (yyyy)

Please! Do not mark below this line

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

Feet heightft

Inches heightin

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

weight

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)* mdcr

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

If Other, please specify.

dothprov1-10
text

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

1 ☐ 0 times → *Go to Question B4.*
2 ☐ 1-2 times
3 ☐ 3-4 times
4 ☐ 5-6 times
5 ☐ 7-10 times
6 ☐ 11-20 times
7 ☐ 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? cvisphs

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

1 ☐ Less than 1 year from now
2 ☐ 1-2 years from now
3 ☐ 3-4 years from now
4 ☐ 5 or more years from now
5 ☐ Never
6 ☐ 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)? ervisit

☐☐ 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? skinck

1 ☐ Once a month

2 ☐ Every few months

3 ☐ Every 6 months

4 ☐ Every year

5 ☐ Never

Continue on next page.

B7. In the past 12 months, has a regular healthcare provider carefully examined your child's whole body for any sign of skin cancer?

skinckdr

2 ☐ No

1 ☐ Yes

3 ☐ Not sure

Please! Do not mark below this line

MEDICAL TESTS

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

When was the last time your child had . . .

7 I don't know if my child ever had one
6 My child had one, but I don't recall when
5 5 or more years ago
4 More than 2 years but less than 5 years ago
3 1-2 years ago
2 Less than 1 year ago
1 Never

		1	2	3	4	5	6	7
a.	An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a MUGA scan? echoexam	☐	☐	☐	☐	☐	☐	☐
b.	An MRI of his/her heart (he/she was placed inside of a scanner, like a long tube)? heartmri	☐	☐	☐	☐	☐	☐	☐
c.	An MRI of the head or brain? headmri	☐	☐	☐	☐	☐	☐	☐
d.	A test to measure his/her bone strength or bone mineral density (such as a DEXA scan)? dexaexam	☐	☐	☐	☐	☐	☐	☐
e.	An ultrasound of the thyroid gland? thyus	☐	☐	☐	☐	☐	☐	☐
f.	An ultrasound of the carotid arteries (blood vessels in the neck)? carotidus	☐	☐	☐	☐	☐	☐	☐
g.	A skin exam for skin cancer by a healthcare provider? skinexam	☐	☐	☐	☐	☐	☐	☐

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).**

	2 No / 1 Yes / 3 Not sure	If yes, age at first use (years)	If yes, is he/she currently taking? 1 Yes / 2 No
1. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil----------	bcpill	abcpill	bcpill2
If yes, specify the name of the drug(s) or indicate you do not know the specific name bcpillc1-6 coded			
2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle-------	estprog	aestprog	estprog2
If yes, specify the name of the drug(s) or indicate you do not know the specific name estproc1-5 coded			
3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate----------	testot	atestos	testos2
If yes, specify the name of the drug(s) or indicate you do not know the specific name testosc1-4 coded			
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)----------	diadrug	adiabdr	diabdr2
If yes, specify the name of the drug(s) or indicate you do not know the specific name diabdrc1-5 coded			

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).

	2 No	1 Yes	3 Not sure	If yes, age at first use	If yes, is he/she currently taking? 2 No	1 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 ☐☐	☐	☐
	hrtdrg			ahrtdrg	hrtdrg2	
If yes, specify the name of the drug(s) or indicate you do not know the specific name hrtdrgc1-6 coded						
6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil	☐	☐	☐	☐☐	☐	☐
	chodrg			achodrg	chodrg2	
If yes, specify the name of the drug(s) or indicate you do not know the specific name chodrgc1-5 coded						
7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA, CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR IRREGULAR HEART BEAT	☐	☐	☐	☐☐	☐	☐
	hrtcon			ahrtcon	hrtcon2	
If yes, specify the name of the drug(s) or indicate you do not know the specific name hrtconc1-9 coded						
8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine), Levothroid, or others	☐	☐	☐	☐☐	☐	☐
	thydrug			athydrg	thydrug2	
If yes, specify the name of the drug(s) or indicate you do not know the specific name thydrgc1-4 coded						

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).**

	3 Not sure / 1 Yes / 2 No	If yes, age at first use	If yes, is he/she currently taking? 1 Yes / 2 No
9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil----------	☐ ☐ ☐ antidep	years ☐☐ adepress	☐ ☐ depress2
If yes, specify the name of the drug(s) or indicate you do not know the specific name depressc1-15 coded			
10. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Strattera, Aricept (donepezil), or Provigil (modafinil)----------	☐ ☐ ☐ atten	☐☐ aatten	☐ ☐ atten2
If yes, specify the name of the drug(s) or indicate you do not know the specific name attenc1-6 coded			
11. OTHER PRESCRIBED DRUGS----------	☐ ☐ ☐ othpdrug	☐☐ aopdrug	☐ ☐ opdrug2
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. opdrugc1-20 opdrugr1-20 coded			

Please! Do not mark below this line

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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. . .

		2 No	1 Yes, and the condition is still present	3 Yes, but the condition is no longer present	4 Not sure	If yes, age at first occurrence (years)	Has your child received care for this in the last two years? 2 No	1 Yes
D1. Had one or more missing teeth because they did not develop?	mistth	☐	☐	☐	☐	a_mistth		c_mistth
D2. Had a lack of or decreased amount of enamel on surface of teeth (hypoplasia)?	enamel	☐	☐	☐	☐	a_enamel		c_enamel
D3. Had abnormal shaped (small or malformed) teeth?	abntth	☐	☐	☐	☐	a_abntth		c_abntth
D4. Had abnormal root development?	abnrt	☐	☐	☐	☐	a_abnrt		c_abnrt
D5. Had difficulty in producing saliva (dry mouth) that required treatment such as artificial saliva?	drymth	☐	☐	☐	☐	a_drymth		c_abnrt
D6. Had severe gingivitis or gum disease requiring surgery or deep cleaning?	gumdis	☐	☐	☐	☐	a_gumdis		c_gumdis
D7. Had root canal therapy?	rtcanl	2☐ No	1☐ Yes	3☐ Not Sure		a_rtcanl		c_rtcanl
D8. Had more than 5 cavities?	cavities	2☐ No	1☐ Yes	3☐ Not Sure				
D9. Lost 6 or more teeth due to decay or gum disease?	lost6th	2☐ No	1☐ Yes	3☐ Not Sure				
D10. Worn a dental bridge (for missing or removed teeth)?	dntbrg	☐	☐	☐	☐	a_dntbrg		c_dntbrg
D11. Worn removable dentures (complete or partial upper or lower or both)?	dentur	☐	☐	☐	☐	a_dentur		c_dentur
D12. Worn a prosthesis to lift his/her palate to improve the quality of his/her voice?	dntpros	☐	☐	☐	☐	a_dntpros		c_dntpros
D13. Had other dental treatment or surgery?	othdntx	2☐ No	1☐ Yes	3☐ Not Sure		a_othdntx		c_othdntx

If yes, explain type of procedure.

dothdntx1-5 text

		2 No	1 Yes, and the condition is still present	3 Yes, but the condition is no longer present	4 Not sure	If yes, age at first occurrence (years)	Has your child received care for this in the last two years? 2 No	1 Yes
D14. Had any other dental problems?	othdnpr	☐	☐	☐	☐	a_othdnpr		c_othdnpr

If yes, explain type of procedure.

dothdnpr1-3 text

Please! Do not mark below this line

D15. Has your child ever had dental braces? dntbrace

2 ☐ No

1 ☐ Yes

3 ☐ Don't know

D16. Does your child currently have dental insurance? dntins

2 ☐ No

1 ☐ Yes

3 ☐ Don't know

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

2 ☐ No

1 ☐ Yes

3 ☐ Don't know

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

2 ☐ No

1 ☐ Yes

3 ☐ 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)*

	2 No	1 Yes	3 Not sure
a. Acupuncture amaccp	☐	☐	☐
b. Biofeedback ambio	☐	☐	☐
c. Chiropractor amchir	☐	☐	☐
d. Crystals/magnets ammag	☐	☐	☐
e. Nutritional supplements (such as Omega-3 fatty acids) amnusp	☐	☐	☐
f. Herbal remedies (such as St. John's Wort, Echinacea) amhebr	☐	☐	☐
g. Homeopathic remedies amhopa	☐	☐	☐
h. Hypnosis/guided imagery amhyp	☐	☐	☐
i. Massage/body work ammas	☐	☐	☐
j. Meditation/relaxation amrelx	☐	☐	☐
k. Modified diet (gluten-free, vegan) ammodi	☐	☐	☐
l. Naturopathic treatments amnatu	☐	☐	☐
m. Spiritual healing/prayer amspir	☐	☐	☐
n. Therapeutic touch amther	☐	☐	☐
o. Vitamins/minerals (not regular multi-vitamin, but high dose C, zinc, etc.) amvit	☐	☐	☐
p. Yoga/Tai Chi/Qi Gong/special exercise amyoga	☐	☐	☐
q. Other amoth	☐	☐	☐

If Other, please specify.

damoth1-4

text

Please! Do not mark below this line

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. . .

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

F1. Hearing loss requiring a hearing aid? hear — a_hear
F2. Deafness in both ears not completely corrected by hearing aid? deaf1 — a_deaf1
F3. Deafness in only one ear not completely corrected by hearing aid? deaf2 — a_deaf2
F4. Tinnitus or ringing in the ears? tinn — a_tinn
F5. Persistent dizziness or vertigo? dizzy — a_dizzy
F6. Hearing loss, not requiring a hearing aid? hearlos — a_hearlos
F7. Any other hearing problems? othhpr — a_othpr

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

dothhpr1-3
aothhpr1-3
coded

F8. Legally blind in only one eye? oneeye — a_oneeye

If yes, does he/she have any sight in this eye?
2☐ No 1☐ Yes onesight

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

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

F9. Legally blind in both eyes? twoeye — a_twoeye

If yes, does he/she have any sight? twosight
2☐ No 1☐ Yes

F10. Cataracts? catar — a_catar
F11. Glaucoma (excess pressure in the eyeball)? glauc — a_glauc
F12. Problems with double vision? dblvis — a_dblvis
F13. A detached retina or any other condition of the retina? retina — a_retina

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

dretina1-4
aretina1-4
coded

F14. Crossed or turned eyes (strabismus)? croseye — a_croseye
F15. Lazy eye (amblyopia)? lazyeye — a_lazyeye
F16. Any other trouble seeing with one or both eyes even when wearing glasses? othsee — a_othsee
F17. Very dry eyes requiring eye drops or ointment? dryeyes — a_dryeye
F18. Any other eye problems? otheye — a_otheye

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

dotheye1-3
aotheye1-3
coded

Please! Do not mark below this line

5395120106

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. . .

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence
years

F19. Stammering or stuttering speech? . . . . . stammr ☐ ☐ ☐ ☐ a_stammr

F20. Any other speech defects? . . . . . othspk ☐ ☐ ☐ ☐ a_othspk

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

dothspk1-4 coded

aothspk1-4

F21. Abnormal sense of taste? . . . . abtast ☐ ☐ ☐ ☐ a_abtast

F22. Loss of taste lasting for 3 months or more? . . . . . tastlos ☐ ☐ ☐ ☐ a_tastlos

F23. Loss of smell lasting for 3 months or more? . . . . . smellos ☐ ☐ ☐ ☐ a_smellos

URINARY SYSTEM

G1. Kidney stones? . . . . . kidstn ☐ ☐ ☐ ☐ a_kidstn

G2. REPEATED kidney or bladder infections (more than 3 in any 12 month period)? . . . . . kidinf ☐ ☐ ☐ ☐ a_kidinf

G3. Dialysis? . . . . . dialys ☐ ☐ ☐ ☐ a_dialys

G4. Blood in his/her urine? . . . . . urblood ☐ ☐ ☐ ☐ a_urblood

G5. Protein in his/her urine? . . . . . urprot ☐ ☐ ☐ ☐ a_urprot

G6. Urinary incontinence? . . . . . incont ☐ ☐ ☐ ☐ a_incont

G7. Any other kind of kidney, bladder or urinary tract disorder? . . . . . othkud ☐ ☐ ☐ ☐ a_othkud

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

dothkud1-4 coded

aothkud1-4

HEART AND CIRCULATORY SYSTEM

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

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence
years

H1. Congestive heart failure or cardiomyopathy (weak heart muscle)? . . . . . conghf ☐ ☐ ☐ ☐ a_conghf

H2. A myocardial infarction (heart attack)? . . . . . htatt ☐ ☐ ☐ ☐ a_htatt

H3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor? . . . . . arrytm ☐ ☐ ☐ ☐ a_arrytm

H4. Coronary heart disease? . . . . coronh ☐ ☐ ☐ ☐ a_coronh

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

coronh1-4 coded

acoronh1-4

H5. Hypertension (high blood pressure) requiring medication? . . . . . hytmed ☐ ☐ ☐ ☐ a_hytmed

If yes, does he/she currently take hypertension medication?
2☐ No 1☐ Yes hytmed2

H6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)? . . . . . angina ☐ ☐ ☐ ☐ a_angina

H7. Pericarditis or fluid around the heart? . . . . . percis ☐ ☐ ☐ ☐ a_percis

H8. Pericardial constriction (scarring or tightness of the sac around the heart)? . . . . . percon ☐ ☐ ☐ ☐ a_percon

H9. Stiff or leaking heart valves? . . slvalv ☐ ☐ ☐ ☐ a_slvalv

H10. Blood clot in head, lung, arm, leg, or pelvis? . . . . . bclot ☐ ☐ ☐ ☐ a_bclot

H11. Does exercise cause severe chest pain, shortness of breath, or irregular heart beat? . . . . . exerpn ☐ ☐ ☐ ☐ a_exerpn

Please! Do not mark below this line

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

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence
years

H12. High cholesterol (or triglyceride) requiring prescription medication? trigdr1 ☐ ☐ ☐ ☐ ☐ a_trigdr1

If yes, does he/she currently take medication for this?
2☐ No 1☐ Yes trigdr2

H13. Any other heart or circulatory problems? othhrt ☐ ☐ ☐ ☐ ☐ a_othhrt

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

dothhrt1-4
coded
aothhrt1-4

H14. Has anyone in your child's immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55? fmi55

2☐ No 1☐ Yes 3☐ Unsure

HORMONAL SYSTEMS

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

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence

I1. An overactive thyroid gland (hyperthyroid)? ovthyr ☐ ☐ ☐ ☐ a_ovthyr

I2. An underactive thyroid gland (hypothyroid)? unthyr ☐ ☐ ☐ ☐ a_unthyr

I3. Thyroid nodules? thynod ☐ ☐ ☐ ☐ a_thynod

I4. Swollen or enlarged thyroid gland? thyenl ☐ ☐ ☐ ☐ a_thyenl

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

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence
years

I5. Diabetes that can be controlled with diet? diabd ☐ ☐ ☐ ☐ a_diabd

I6. Diabetes controlled with pills or tablets? diabp ☐ ☐ ☐ ☐ a_diabp

I7. Diabetes controlled with insulin shots? diabi ☐ ☐ ☐ ☐ a_diabi

I8. Deficiency of growth hormone? ghdef ☐ ☐ ☐ ☐ a_ghdef

I9. Has your child received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)? injghr ☐ ☐ ☐ ☐ a_injghr

If yes, does he/she currently take injections of growth hormone? injghr_c
2☐ No 1☐ Yes

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

I11. Has your child ever broken a bone? bknbon ☐ ☐ ☐ ☐ a_bknbon

If yes, describe <u>all</u> occurrences of broken bones. List the age for each individual occurrence.

bknbon1-24
coded
abknbon1-24

I12. Any other hormonal problems? othhor ☐ ☐ ☐ ☐ a_othhor

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

dothhor1-4
coded
aothhor1-4

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?

period

2 ☐ No 1 ☐ Yes

If yes, age at first occurrence: a_period ☐☐

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**

periodyr periodmo

I15. **FEMALES** - Which one of the following statements best describes your child? **(Select only one)** pdesc

1 ☐ a. She is having regular periods and she is not taking birth control pills or female hormones (example: Premarin, estrogen)

2 ☐ b. She is having regular periods but she is using birth control pills to prevent a pregnancy

3 ☐ c. Her menstrual periods are irregular and she is taking birth control pills or female hormones to regulate her periods

8 ☐ d. Her menstrual periods are irregular but she is not using birth control pills or female hormones to regulate her periods

4 ☐ e. She is currently pregnant

5 ☐ f. She is not having menstrual periods naturally but she is taking birth control pills or female hormones

6 ☐ g. She is not having menstrual periods naturally and she is not taking birth control pills or female hormones

7 ☐ h. Other

If Other, please describe.

pother text

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)** pstopwhy

1 ☐ Normal or early menopause

2 ☐ Surgery (example: a hysterectomy)

3 ☐ Pregnancy

9 ☐ Don't know

4 ☐ Other

If Other, please describe.

pstopdes text

RESPIRATORY SYSTEM

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

		2 No	1 Yes, and the condition is still present	3 Yes, but the condition is no longer present	4 Not sure	If yes, age at first occurrence (years)
J1.	Asthma? asthma	☐	☐	☐	☐	a_asthma
J2.	Chronic cough or shortness of breath for more than one month? ccough	☐	☐	☐	☐	a_ccough
J3.	Has your child had a need for extra oxygen? evoxy	☐	☐	☐	☐	a_evoxy
J4.	Pneumonia, 3 or more times in the past 2 years? pneum3	☐	☐	☐	☐	a_pneum3
J5.	Emphysema or other chronic obstructive pulmonary disease (COPD)? emphma	☐	☐	☐	☐	a_emphma
J6.	Lung fibrosis or "scarring" of the lung? lngfib	☐	☐	☐	☐	a_lngfib
J7.	Problems with breathing while at rest that lasted for more than 3 months? brhprb	☐	☐	☐	☐	a_brhprb
J8.	Any other breathing or lung problems? othres	☐	☐	☐	☐	a_othres

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

dothres1-6 coded

aothres1-6

Please! Do not mark below this line

1932120109

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. . .

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No
If yes, age at first occurrence
years

K1. Hepatitis? . . . . . hepats ☐ ☐ ☐ ☐ a_hepats

If yes, what type(s)? ***(Mark all that apply)*** hepatyp
- ☐ Hepatitis A hepatyp_a
- ☐ Hepatitis B hepatyp_b
- ☐ Hepatitis C hepatyp_c
- ☐ Don't know hepatyp_dk
- ☐ Other hepatyp_ot

K2. Cirrhosis of the liver? . . . . . cirliv ☐ ☐ ☐ ☐ a_cirliv

K3. Fatty liver?. . . . . faliv ☐ ☐ ☐ ☐ a_fatliv

K4. Any other liver trouble? . . . . . othliv ☐ ☐ ☐ ☐ a_othliv

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

dothliv1-3 aothliv1-3 coded

K5. Intestinal (colon) polyps? . . . . . polyps ☐ ☐ ☐ ☐ a_polyps

K6. Esophageal strictures (narrowing of the esophagus)?. . . . . esophs ☐ ☐ ☐ ☐ a_esophs

K7. Rectal or anal fistula? . . . . . recfis ☐ ☐ ☐ ☐ a_recfis

K8. Rectal or anal stricture (narrowing or scarring)? . . . . . recstr ☐ ☐ ☐ ☐ a_recstr

K9. Stricture (narrowing or scarring) of the small or large intestine?. . . . . intestr ☐ ☐ ☐ ☐ a_intestr

K10. Any other stomach or digestive trouble? . . . . . othdig ☐ ☐ ☐ ☐ a_othdig

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

dothdig1-6 aothdig1-6 coded

SURGICAL PROCEDURES

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

3 Not sure
1 Yes
2 No
If yes, age at first occurrence
years

L1. Amputation of an arm, leg, hand, foot?. . . . . amputn ☐ ☐ ☐ a_amputn

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

damputn1-3 aamputn1-3 coded

L2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)?. . . . . sclsis ☐ ☐ ☐ a_sclsis

L3. Other surgery of spinal cord or spine?. . . . . othspn ☐ ☐ ☐ a_othspn

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

dothspn1-4 aothapn1-4 coded

L4. Leg lengthening or shortening procedures? . . . . . lensht ☐ ☐ ☐ a_lensht

L5. Joint replacement?. . . . . jntrep ☐ ☐ ☐ a_jntrep

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

djntrep1-7 ajntrep1-7 coded

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.

3 Not sure
1 Yes
2 No
If yes, age at first occurrence
years

L6. Other bone surgery? . . . . . othbon ☐ ☐ ☐ a_othbon

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

dothbon1-6
coded
aothbon1-6

L7. Coronary artery bypass surgery? . . . . . bypass ☐ ☐ ☐ a_bypass

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

L9. Heart catheterization ("heart cath")? . . . . . htcath ☐ ☐ ☐ a_htcath

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

L11. Surgery for heart valve replacement? . . . . . valverp ☐ ☐ ☐ a_valverp

L12. Surgery for pacemaker? . . . . pacem ☐ ☐ ☐ a_pacem

L13. Other heart surgery? . . . . . othht ☐ ☐ ☐ a_othht

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

dothht1-3
coded
aothht1-3

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

3 Not sure
1 Yes
2 No
If yes, age at first occurrence
years

L14. Surgery to repair a fistula (an abnormal connection between the intestine or rectum and other structures? . . . . . fistul ☐ ☐ ☐ a_fistul

L15. Surgery for intestinal obstruction (blocked intestines)? . . . . . intobs ☐ ☐ ☐ a_intobs

L16. Colostomy or ileostomy (stool going into a bag)? . . . . colsty ☐ ☐ ☐ a_colsty

L17. Removal of part or all of the colon . . . . . colosty_col ☐ ☐ ☐ a_colon

L18. Removal of part or all of the rectum. . . . . colosty_rec ☐ ☐ ☐ a_rectum

L19. Biopsy or removal of lump in thyroid gland? . . . . . biothy ☐ ☐ ☐ a_biothy

L20. Removal of part or all of the thyroid gland? . . . . . remthy ☐ ☐ ☐ a_remthy

L21. Removal of the spleen? . . . . remspl ☐ ☐ ☐ a_remspl

L22. Bladder, ureter, or kidney surgery? . . . . . bladsur ☐ ☐ ☐ a_bladsur

L23. Removal of all or part of a kidney? . . . . . remkidn ☐ ☐ ☐ a_remkidn

L24. Liver or gall bladder surgery? livsur ☐ ☐ ☐ a_livsur

L25. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid? . . . . . vpshunt ☐ ☐ ☐ a_vpshunt

L26. Breast biopsy? . . . . . brstbio ☐ ☐ ☐ a_brstbio

L27. Breast-conserving or breast-sparing surgery (lumpectomy)? . . . . . lumpsur ☐ ☐ ☐ a_lumpsur

L28. Mastectomy or removal of a breast? . . . . . mastec ☐ ☐ ☐ a_mastec

If yes, was one or both breasts removed? brstspe

1 ☐ Left only 2 ☐ Right only 3 ☐ Both

Please! Do not mark below this line

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

3 Not sure
1 Yes
2 No
If yes, age at first occurrence
years

L29. Any lung surgery? . . . . . lungsur ☐ ☐ ☐ a_lungsur

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

dlngsur1-3
coded
alngsur1-3

L30. Periodontal (gum) surgery? . gumsur ☐ ☐ ☐ a_gumsur

L31. Heart transplant? . . . . . hrttrn ☐ ☐ ☐ a_hrttrn

L32. Lung transplant? . . . . . lngtrn ☐ ☐ ☐ a_lngtrn

L33. Kidney transplant? . . . . . kidtrn ☐ ☐ ☐ a_kidtrn

L34. Liver transplant? . . . . . trasliv ☐ ☐ ☐ a_trasliv

L35. Bone marrow transplant? . . . bmrtrn ☐ ☐ ☐ a_bmrtrn

L36. Other organ transplant? . . . othtrn ☐ ☐ ☐ a_othtrn

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

dothtrn1-3
coded
aothtrn1-3

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

3 Not sure
1 Yes
2 No
If yes, age at first occurrence
years

L37. Cataract surgery? . . . . . catsrg ☐ ☐ ☐ a_catsrg

Males → Go to Question L42.

L38. Removal of one ovary? . . . . reoneov ☐ ☐ ☐ a_reoneov

L39. Removal of both ovaries? . . . retwoov ☐ ☐ ☐ a_retwoov

L40. Removal of uterus? . . . . . reutrs ☐ ☐ ☐ a_reutrs

L41. Surgery of the vagina? . . . . vagsrg ☐ ☐ ☐ a_vagsrg

Females → Go to Question L45.

L42. Removal of one testis? . . . . reonete ☐ ☐ ☐ a_reonete

L43. Removal of both testes? . . . . retwote ☐ ☐ ☐ a_retwote

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

L45. Any other surgery? . . . . . othsg ☐ ☐ ☐ a_othsg

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

dothsg1-15
coded
aothsg1-15

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. . .

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No

If yes, age at first occurrence

years

M1. Problems with learning or memory? . . . . . prbmem ☐ ☐ ☐ ☐ a_prbmem

If yes and still present, please rate the severity of these problems: prbmem2

1 ☐ Mild; does not interfere with work, school, or general life. My child does/did need special help in school.

2 ☐ Moderate; interferes with work, school, or general life, but my child is capable of independent living. My child uses/used special help in school.

3 ☐ Severe; My child is significantly impaired in his/her school or work performance or in general life.

4 ☐ 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? . . eplpsy ☐ ☐ ☐ ☐ a_eplpsy

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

deplpsy1-6 coded

aeplpsy1-6

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

2 ☐ No 1 ☐ Yes eplpsy2

If yes, name of medications

meplpsy1-6 coded

Date of last seizure

seizdt ☐☐ / ☐☐ / ☐☐☐☐

M M D D Y Y Y Y

4 Not sure
3 Yes, but the condition is no longer present
1 Yes, and the condition is still present
2 No

If yes, age at first occurrence

years

M3. Migraine? . . . . . migrne ☐ ☐ ☐ ☐ a_migrne

M4. Other severe headaches? . . . . hdache ☐ ☐ ☐ ☐ a_hdache

M5. Other repeated headaches? . . rhache ☐ ☐ ☐ ☐ a_rhache

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

mhdache1-8 coded

ahdache1-8

M6. Problems with balance, equilibrium, or ability to reach for or manipulate objects? . . balnce ☐ ☐ ☐ ☐ a_balnce

If yes and still present, please rate the severity of these problems: balnce2

1 ☐ Mild; does not affect walking or daily routine.

2 ☐ Moderate; it is bothersome and affects walking but my child is able to do daily routine.

3 ☐ Severe; this problem significantly affects walking and daily routine.

4 ☐ Disabling; My child requires a wheelchair or cannot walk because of this problem.

M7. Tremors or problems with movements? . . . . . tremor ☐ ☐ ☐ ☐ a_tremor

M8. Problems chewing or swallowing solids or liquids? . chwswl ☐ ☐ ☐ ☐ a_chwswl

M9. Decreased sense of touch or feeling in hands, fingers, arms or legs? . . . . . touch ☐ ☐ ☐ ☐ a_touch

M10. Prolonged pain in arms or legs. . . . . armlegpn ☐ ☐ ☐ ☐ a_armlegp

M11. Prolonged pain in back . . . . backpn ☐ ☐ ☐ ☐ a_backpn

M12. Abnormal sensation in arms, legs or back? . . . . . absens ☐ ☐ ☐ ☐ a_absens

M13. Weakness or inability to move arm(s)? . . . . . movarm ☐ ☐ ☐ ☐ a_movarm

Please! Do not mark below this line

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

	2 No	1 Yes, and the condition is still present	3 Yes, but the condition is no longer present	4 Not sure	If yes, age at first occurrence (years)
M14. Weakness or inability to move leg(s)? movleg	☐	☐	☐	☐	a_movleg
M15. Paralysis of any kind? parlys	☐	☐	☐	☐	a_parlys

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

dparlys1-5

coded

aparlys1-5

M16. Stroke? srk1 ☐ ☐ ☐ ☐ — a_srk1 ☐☐

If no → Go to M18.

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

a. Did the symptoms last more than 24 hours?

2 ☐ No 1 ☐ Yes srkday

Did the stroke affect:

b. Speech. srkspch	☐	☐	☐	☐
c. Balance and coordination. srkbal	☐	☐	☐	☐
Only one side of the body srkbal1	☐	☐	☐	☐
Both sides of the body . . . srkbal2	☐	☐	☐	☐
d. Did your child lose consciousness? srkcons	☐	☐	☐	☐
e. Did your child experience sensory loss (vision, taste, smell)? strsens	☐	☐	☐	☐
Only one side of the body srksens1	☐	☐	☐	☐
Both sides of the body . . . srksens2	☐	☐	☐	☐
f. Did your child have weakness or inability to move arm(s)? srkmar	☐	☐	☐	☐
Only one side of the body srkmar1	☐	☐	☐	☐
Both sides of the body . . . srkmar2	☐	☐	☐	☐
g. Did your child have weakness or inability to move leg(s)? srkmlg	☐	☐	☐	☐
Only one side of the body srkmlg1	☐	☐	☐	☐
Both sides of the body . . . srkmlg2	☐	☐	☐	☐

	2 No	1 Yes, and the condition is still present	3 Yes, but the condition is no longer present	4 Not sure
h. Did your child have paralysis of any kind? srkpar	☐	☐	☐	☐
Only one side of the body srkpar1	☐	☐	☐	☐
Both sides of the body . . . srkpar2	☐	☐	☐	☐

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

dsrkpar1-7

coded

asrkpar1-7

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

M18. Any other brain or nervous system problems? othbns ☐ ☐ ☐ ☐ — If yes, age at first occurrence (years) a_othbns ☐☐

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

dbnspro1-7

coded

abnspro1-7

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

2 ☐ No

1 ☐ Yes, but my child is able to drive

4 ☐ Yes, my child is unable to drive

3 ☐ Unsure, my child does not drive

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

2 ☐ No

1 ☐ Yes, but my child is able to work

4 ☐ Yes, my child is unable to work

3 ☐ Unsure, my child does not work

Please! Do not mark below this line

Human papillomavirus vaccination

N1. MALES AND FEMALES 9 OR OLDER- HPV is the Human Papillomavirus. The HPV vaccine is a series of 2 or 3 shots, depending on what age the shots are started. Has your child ever received the HPV shot or vaccine? hpvvacfm

1 ☐ Yes
2 ☐ No → *Go to Question N4.*
3 ☐ Don't Know → *Go to Question N4.*

N2. How old was your child when your child received the first dose of the HPV vaccine? . . . . . ☐☐

a_hpvvacfm

N3. How many shots of the HPV vaccine did your child receive? nhpvvacfm

1 ☐ 1 shot 2 ☐ 2 shots 3 ☐ 3 shots 4 ☐ Don't Know

N4. How likely is it that your child will receive the HPV vaccine in the next 12 months? hpvvac_12mons

1 ☐ Very likely
2 ☐ Somewhat likely
3 ☐ Not too likely
4 ☐ Not likely at all
5 ☐ Refused
6 ☐ Don't know

N5. Has a doctor or other health care professional ever recommended that your child receive HPV shots? hpv_recommend

2 ☐ No → *Go to Question N7.*
1 ☐ Yes → *Go to Question N6.*

N6. At what age did the doctor or health care professional recommend that your child should start receiving the HPV shots? hpv_age

1 ☐ Before age 11
2 ☐ 11 or 12 years of age
3 ☐ 13 or 14 years of age
4 ☐ 15 or 16 years of age
5 ☐ 17 or 18 years of age
6 ☐ After 18 years of age
7 ☐ No specific age was recommended or discussed
8 ☐ Don't know
9 ☐ Refused

Influenza vaccination

N7. During the past 12 months, has your child had either a flu shot or a flu vaccine that was sprayed in his/her nose? fluvac

1 ☐ Yes
2 ☐ No
3 ☐ Don't Know

N8. 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? pneumovac

1 ☐ Yes
2 ☐ No
3 ☐ Don't Know

Continue on next page.

CANCER, LEUKEMIA, OR TUMOR

O1. At any time was your child diagnosed with cancer, leukemia, tumor, or similar illness? cancer1c

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

1 ☐ Yes

O2. What was the name of this disease?

cond1c text

O3. Did he/she have treatment for this disease? txcond1c

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

1 ☐ Yes → **O3a. What treatments did he/she receive?** ***(Mark all that apply)*** tx1c

☐ Chemotherapy tx1c_chemo

☐ Radiation therapy tx1c_rt

☐ Surgery tx1c_surg

Continue on next page.

Please! Do not mark below this line

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? hospadm

2 ☐ No → *Go to Section Q, next page.*

1 ☐ Yes

hosadmn

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?

ha1reason1-5 coded

P3a. What procedures/surgeries were performed?

ha1proced1-5 coded

P3b. Where was your child hospitalized?

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

P3c. Date of first hospitalization:

☐☐ Month (mm) ha1mo

☐☐☐☐ Year (yyyy) ha1yr

P4. What was the reason for the second hospitalization?

ha2reason1-4 coded

P4a. What procedures/surgeries were performed?

ha2proced1-4 coded

P4b. Where was your child hospitalized?

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

P4c. Date of second hospitalization:

☐☐ Month (mm) ha2mo

☐☐☐☐ Year (yyyy) ha2yr

Please use a separate sheet of paper for additional hospitalizations

ha3reason1-4
ha3proced1-4
ha3mo
ha3yr

Please! Do not mark below this line

PREGNANCY AND OFFSPRING

Female

Q1. Has your child ever had any pregnancies? pregyn_f

2 ☐ No → *Go to page R1a, next page.*

1 ☐ Yes

Q2. Is your daughter currently pregnant? pregnow_f

2 ☐ No

1 ☐ Yes

Continue to Question Q5 below.

Male

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

2 ☐ No → *Go to page R1a, next page.*

1 ☐ Yes

Q4. Is she currently pregnant? pregnow_m

2 ☐ No

1 ☐ 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

		1 Live birth	2 Stillbirth	3 Miscarriage	4 Medical abortion	5 Currently pregnant	Your child's age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
Pregnancy 1.	pregout1	☐	☐	☐	☐	☐	a_preg1	a_ppreg1	wkspreg1
Pregnancy 2.	pregout2	☐	☐	☐	☐	☐	a_preg2	a_ppreg2	wkspreg2
Pregnancy 3.	pregout3	☐	☐	☐	☐	☐	a_preg3	a_ppreg3	wkspreg3
Pregnancy 4.	pregout4	☐	☐	☐	☐	☐	a_preg4	a_ppreg4	wkspreg4
Pregnancy 5.	pregout5	☐	☐	☐	☐	☐	a_preg5	a_ppreg5	wkspreg5

Please! Do not mark below this line

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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 <u>your child was born with</u>, 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. . .

	2 No	1 Yes	3 Not sure
a. Ataxia telangiectasia. . . . . gcataxtg	☐	☐	☐
b. Beckwith-Wiedemann syndrome . . . . . gcbwsynd	☐	☐	☐
c. Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2) gcnf2	☐	☐	☐
d. Bloom's syndrome . . . . . gcbloom	☐	☐	☐
e. Down syndrome . . . . . gcdown	☐	☐	☐
f. Klinefelter's syndrome. . . . . gcklinel	☐	☐	☐
g. Fanconi's anemia. . . . . gcfanemia	☐	☐	☐
h. Multiple exostoses . . . . . gcmexos	☐	☐	☐
i. Familial adenomatous polyposis (FAP or Gardner syndrome). . . . . gcfap	☐	☐	☐
j. Neurofibromatosis (Type 1). gcnf1	☐	☐	☐
k. Nevoid basal cell carcinoma syndrome . . gcnevbcc	☐	☐	☐
l. Turner's syndrome. . . . . gcturner	☐	☐	☐
m. Von Hippel-Lindau syndrome. . . . . gcvhl	☐	☐	☐
n. Wiskott-Aldrich syndrome. . . . . gcwasynd	☐	☐	☐
o. Xeroderma pigmentosum. . . . . gcpigment	☐	☐	☐
p. Polycystic kidney disease. . . . . gcpkd	☐	☐	☐
q. WAGR syndrome. . . . . gcwagr	☐	☐	☐
r. Li-Fraumeni syndrome (p53 gene abnormality). gcp53	☐	☐	☐
s. Any other genetic disorder . . . . . gcoth	☐	☐	☐

If yes, describe this disorder.

dgcoth1-4 coded

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)***

gc

My child's . . .	What conditions?
☐ Mother → gc_mom	dgcmom1-4 coded
☐ Father → gc_dad	dgcdad1-4 coded
☐ Full brother → gc_bro	dgcbro1-4 coded
☐ Full sister → gc_sis	dgcsis1-4 coded
☐ Son → gc_son	dgcson1-4 coded
☐ Daughter → gc_dau	dgcdau1-4 coded

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 <u>ever</u> had genetic counseling for cancer risk? grcounsel

2 ☐ No

1 ☐ Yes

Continue on next page.

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

		2 No	1 Yes	3 Not sure
a. Cleft lip or palate	bdcleft	☐	☐	☐
b. Club foot	bdclub	☐	☐	☐
c. Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime)	bdmarks	☐	☐	☐
d. Deafness or impaired hearing at birth	bdhear	☐	☐	☐
e. Blindness or difficulty seeing at birth	bdsee	☐	☐	☐
f. Eyes different colors or missing an iris (the colored part of the eye)	bdeye	☐	☐	☐
g. Hydrocephalus (excessive water around or within the brain)	bdhydro	☐	☐	☐
h. Spina bifida or other neural tube defect	bdnt	☐	☐	☐
i. Unusually small head (microcephaly)	bdhead	☐	☐	☐
j. Unequal sized limbs (hemihypertrophy)	bdlimbs	☐	☐	☐
k. Extra fingers, deformed chest, shortened limbs or any other skeletal abnormality	bdskel	☐	☐	☐
l. Hole in the heart or other congenital heart defect	bdheart	☐	☐	☐

If other, please specify.

dbdhrt1-4 coded

		2 No	1 Yes	3 Not sure
m. Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines)	bddigest	☐	☐	☐
n. Any kidney, bladder, or genital abnormalities	bdurin	☐	☐	☐
o. Undescended testes (males only)	bdtestes	☐	☐	☐
p. Any other birth defects	bdoth	☐	☐	☐

If other, please specify.

dbdoth1-5 coded

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)***

bd

My child's . . .		What conditions?	
☐ Mother	bd_mom	dbdmom1-4 coded	
☐ Father	bd_dad	dbddad1-4 coded	
☐ Full brother	bd_bro	dbdbro1-4 coded	
☐ Full sister	bd_sis	dbdsis1-4 coded	
☐ Son	bd_son	dbdson1-4 coded	
☐ Daughter	bd_dau	dbddau1-4 coded	

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

catypes

My child's . . .		What types?	
☐ Mother	catypes_mom	dcamom1-4 coded	
☐ Father	catypes_dad	dcadad1-4 coded	
☐ Full brother	catypes_bro	dcabro1-4 coded	
☐ Full sister	catypes_sis	dcasis1-4 coded	
☐ Son	catypes_son	dcason1-4 coded	
☐ Daughter	catypes_dau	dcadau1-4 coded	

Please! Do not mark below this line

CONTACT INFORMATION

1. Does your child use a cell phone? cellyn

☐ Yes 1 ☐ No 2 → *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)? smartyn

1☐ Yes 2☐ No

3. Which of the following types of devices does your child use to access the internet? devices
(Mark all that apply)

☐ Computer or laptop devices_comp
☐ Tablet (iPad or similar) devices_tab
☐ Smartphone devices_smrtp
☐ Other, specify: devices_oth text othdevs1-2
☐ My child does not access the internet devices_noint

Do you have an email address we could use to contact you? emailyn
2☐ No 1☐ Yes →
This will not be shared with individuals outside of St. Jude.

Your Email Address:
email

We have your current address and phone as:

THE PARENTS OF Name_2

addr
City
State
zipcode
homephone
phonenumber2

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

1☐ Correct 2☐ Not correct 3☐ Moving

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

Address: upaddr			
City: upcity		State: upstate	
Zip code: upzip	Cell phone: upcellph	Home phone: uphomeph	Work phone: upworkph

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: cntname			
Address: cntaddr		Relationship to cntrel	
City: cntcity		State: cntst	
Zip code: cntzip	Cell phone: cntcellph	Home phone: cntph	Work phone: cntphwrk

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:

comments

text

Please! Do not mark below this line

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