LTFU

Long-Term Follow-Up Sibling Survey

St. Jude Children's Research Hospital
Ann & Robert H. Lurie Children's Hospital of Chicago
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
Children's Hospital Colorado
Children's Hospital of Orange County
Children's Hospital of Philadelphia
Children's Hospital of Los Angeles
Children's Hospital of Pittsburgh
Children's Hospitals & Clinics of Minnesota, Minneapolis and St. Paul
Children's Medical Center of Dallas
Children's National Medical Center
City of Hope National Medical Center
Cook Children's Hematology-Oncology Center
Dana-Farber Cancer Institute/ Children's Hospital Boston
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller Children's Hospital
Nationwide Children's Hospital
Riley Hospital for Children - Indiana University
Roswell Park Cancer Institute
Seattle Children's Hospital
St. Louis Children's Hospital
Texas Children's Hospital
Toronto Hospital for Sick Children
UAB/The Children's Hospital of Alabama
University of California at San Francisco
University of Chicago Comer Children's Hospital
University of Michigan - Mott Children's Hospital
University of Minnesota
U.T.M.D. Anderson Cancer Center

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

St. Jude toll-free phone number:
1-800-775-2167

St. Jude e-mail: LTFU@stjude.org

ltfu.stjude.org

Thank you for participating in the Long-Term Follow-Up study as a brother or sister of an individual treated for childhood cancer, leukemia, tumor or a similar illness. Your participation helps to provide us with valuable information in the fight against these serious illnesses of childhood and adolescence.

You can be assured that we will respect your privacy at all times. Your child's name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

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

Please! Do not mark below this line

Survey #023

9665023472

LTFU Consent Form

This form is an informed consent statement that requires your signature if you wish to participate in the study. Please review the following three pages and sign and date at the yellow arrows.

! Watch for this symbol - it indicates that you need to do something at this point in the consent.

INFORMED CONSENT STATEMENT

Note: When we say "you" throughout this document, we mean "you or your child."

LONG-TERM FOLLOW-UP STUDY

We would like to invite you to take part in the Long-Term Follow-Up Study (LTFU) being conducted by St. Jude Children's Research Hospital. This consent form gives you information about the research study. If you agree to take part, you can complete the consent process via the LTFU website or sign this consent document and return it in the self-addressed, stamped envelope you received. The second consent document is a copy for you to keep or you can print a copy from the website.

Before you learn about the study, it is important that you know the following:

- Whether or not you take part in this study is entirely up to you.
- If you decide not to be in the study, or to withdraw from the study at any time, it will not affect your relationship with St. Jude or with the original treating institution.
- This study is being sponsored (receiving financial support to offset a portion of the costs of the study) by the National Cancer Institute.
- The principal investigator (researcher) of this study is Dr. Leslie Robison, who can be reached at 800-775-2167.
- Your study information will be shared with researchers at St. Jude Children's Research Hospital, the LTFU Biopathology Center (Columbus, OH), LTFU Laboratory (Cincinnati, OH), LTFU Statistical Center (Seattle, WA), LTFU Radiation Physics Center (Houston, TX) and LTFU collaborating researchers.

Why is this study being done?

The purpose of this study is to learn about the health of persons who were treated for cancer, leukemia, tumors, or other similar illnesses as children, compared to their siblings (brothers and sisters). We are interested in studying the risk (chance) of second cancers, long-term side effects of chemotherapy and radiation therapy, and your family history of cancer. The information we collect will be used to make recommendations for the treatment and follow-up of future children who are diagnosed with cancer or a similar illness.

How many patients will take part in the study?

About 30,000 people from around the United States and Canada, who were treated as children for cancer or a similar illness, will take part in this study. Additionally, about 8,000 siblings will participate as a study comparison group.

What is involved in this study?

You will complete a set of questions about your health. Answering all of the questions will take about 45 minutes. You may leave blank any questions you are uncomfortable answering. The questionnaire can be completed over the internet at our website or by completing the questionnaire and returning it in the stamped, self-addressed envelope you received. You may also complete it over the phone with a trained interviewer.

The collected information will be entered into a computer for comparison with people who were treated as children for cancer or a similar illness. All of the information collected in this study will be kept private and participants will not be identified in any study reports.

Based on questionnaire answers, you may be contacted in the future to complete additional questionnaires.

This is a long-term study of childhood survivors of cancer or similar illnesses. In the future, you will receive a shorter questionnaire in the mail every other year until the study is finished.

What are the consequences of withdrawing from this study?

You can stop taking part in this study at any time. Whether or not you take part in this study will not affect your relationship with St. Jude or the original treating institution.

What are the risks of the study?

Very rarely, personal information from your records could be given out by accident. To prevent this from happening, electronic data is stored on password protected computers, only study team members work with the data, and study results are reported on the whole group, never identifying one individual in reports. You may become upset by some survey questions and do not have to answer any question that makes you uncomfortable.

What are the benefits of the study?

You may or may not receive a direct benefit from taking part in this study. The information we collect may help us make recommendations for the treatment and follow-up of future children who are diagnosed with cancer or a similar illness.

What other options are there?

Your participation in this study is voluntary. You may choose not to take part in this study.

What about new information?

You will be told of any new information learned during the course of the study, which might cause you to change your mind about staying in the study. You will receive a CCSS Newsletter every six months that contains a study update and other health information that may be helpful to yourself as well as people who were treated for cancer or similar illness. You have the right to learn about the results of the study. If you are interested in learning more about when and how to get the results of this research study, you may contact Dr. Leslie Robison at 901/595-3300 or Dr. Greg Armstrong, Project Director at St. Jude Children's Research Hospital, at 800/775-2167.

What about privacy?

To help us protect your privacy, we have obtained a Certificate of Confidentiality from the federal government. With this Certificate, the researchers cannot be forced to give out your personal information, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other process. The researchers will use the Certificate to block any demands for information that would identify you, except in the cases listed below.
The Certificate cannot be used to resist a demand for information from the United States Government, if that information is used to audit or check federally funded projects or to meet the needs of the U.S. Food and Drug Administration (FDA).

You should know that a Certificate of Confidentiality does not keep you or a member of your family from choosing to give out information about you or your part in this research. If an insurer, employer, or other person gets your written consent to receive research information, then the researchers cannot use the Certificate to keep that information private.

The Certificate of Confidentiality will not keep researchers or hospital staff from making reports required of them. These include reports about suspected child abuse, about diseases that spread from person to person, or about possible threat of harm to yourself or others.

Government agencies oversee research studies involving people. Your research records may be reviewed by the following:

- Food and Drug Administration (FDA)
- National Institutes of Health (NIH)
- Office of Human Research Protection (OHRP)
- St. Jude Children's Research Hospital Institutional Review Board, a committee that reviews the ethics and safety of research studies

By signing this consent form, you are allowing your research records to be reviewed by these persons.

Where can I get more information?

If you have questions regarding this study you may contact the St. Jude Principal Investigator for this study, Dr. Leslie Robison, at 901/595-3300 or Dr. Greg Armstrong, Project Director at St. Jude Children's Research Hospital, at 800/775-2167.

You can get more information about your rights as a research participant by calling the Chairman of the St. Jude Institutional Review Board at 901/595-4357 or the St. Jude Research Participant Advocate (Ombudsman) at 901/595-4644. If you live outside of the Memphis area, you may call 1-866-583-3472 (1-866-JUDE IRB). This is a toll-free call.

IRB Approved Version: July 19, 2011
The following statement describes your/your child's rights as a research participant:

1. You may talk as much as you want with the researchers about the reasons for this study and about its risks.

2. This study may have risks that the researchers or other doctors do not know about now.

3. We may use your information to develop a new product or medical test to be sold. The sponsor, hospital, and researchers may benefit if this happens. There are no plans to pay you if your information is used for this purpose.

4. You will not be charged for being in this research study.

5. If you decide not to be in the study, or to withdraw from the study at any time, it will not affect your relationship with St. Jude.

6. The St. Jude Notice of Privacy Practices tells how your medical information may be used or given to someone outside the hospital. You have the right to read the Notice of Privacy Practices before you sign this form. You can find it at the bottom of every page on the St. Jude Internet website: *www.stjude.org*.

7. You have the right to see, copy, and ask for changes to your protected health information that will be used or given out. This consent form describes any limits to this right, such as research information that you will not see until the end of the study or that will only be used for research.

8. A description of this clinical trial will be available on http://www.ClinicalTrials.gov, as required by U.S. Law. This Website will not include information that can identify you. At most the Website will include a summary of the results. You can search this Website at any time.

9. Federal agencies such as the Food and Drug Administration (FDA), the Office of Human Research Protections (OHRP) or the National Institutes of Health (NIH), St. Jude Children's Research Hospital Institutional Review Board (IRB), as well as other regulatory agencies, committees, or persons involved in overseeing research studies, may review your research and medical record.

10. Information about you collected as part of this study may be given out as explained in this informed consent form.

11. After your records are given to or used by others, St. Jude Children's Research Hospital cannot promise that information will not be given out again. Also, the information given out may no longer be protected by federal privacy laws.

12. St. Jude uses reasonable safeguards and means to protect the security and confidentiality of e-mail/text messaging, fax information or mail sent to and received from you. However, St. Jude cannot guarantee the security and confidentiality of e-mail or text messaging or fax communications or mail. Despite the best efforts of St. Jude to protect private information, e-mails/text messaging or fax can be electronically taken by other users, changed, forwarded, or used without permission or detection. Possible risks include e-mail/text messaging, fax or mail senders can type the wrong address for an e-mail or mail or dial a wrong phone number. Backup copies of an e-mail/text messaging or fax may exist after the sender or receiver has deleted a copy.

13. Permission to use and give out your child's protected health information will end when your child turns 18 years of age (if applicable). At that time, researchers may get your child's consent if they wish to keep using or giving out your child's protected health information.

14. You may take back permission for your records to be used or given out at any time, for any reason, except the following:
    - When that information has already been given out or used based on your permission
    - When the information is needed to maintain the integrity of the study

15. To take back your permission, please fill out a form called a Revocation of Release of Authorization. You may ask for this form by calling the St. Jude Privacy Officer at 901-595-6141. You must mail the form or hand it to the:
    HIPAA Privacy Officer
    St. Jude Children's Research Hospital
    262 Danny Thomas Place
    Memphis, TN 38105

16. If you have more questions about this study, you can call the Principal Investigator of this study, Dr. Leslie Robison, at 901-595-3300.

17. You can get more details about your rights as a research participant by calling the chairman of the Institutional Review Board at 901-595-4357 or the Research Participant Advocate at 901-595-4644. If you are outside of the Memphis area, please call toll-free 1-866-583-3472 (1-866-JUDE IRB).

The staff will give you a copy of this statement.

RESEARCH PARTICIPANT STATEMENT

I have read (or have had read to me) the contents of this document and have been encouraged to ask questions. I have received answers to my questions. I give consent to take part in this research study and authorize the disclosure and use of my/my child's protected health information for the purposes of that research.

! Sign Here

_____ _____

Research Participant/Research Participant's Parent/Guardian Date

Fill in Date

Please! Do not mark below this line

HIPAA Authorization Form

If you sign this form, you are giving St. Jude Children's Research Hospital permission to use or disclose (give out) medical information. It will allow St. Jude to get copies of certain parts of your (your child's) medical record that we may need to review, such as treatment history for your (your child's) childhood illness or records for later illnesses.

LONG-TERM FOLLOW-UP STUDY
HIPAA[1] AUTHORIZATION TO USE AND DISCLOSE
HEALTH INFORMATION FOR RESEARCH

1. Purpose. As a research participant and at my request, I give Greg Armstrong, M.D., M.S.C.E., and the researcher's staff permission to use and disclose my (my child's) health information for a research project called Long-Term Follow-Up (LTFU) Study.

2. Individual Health Information to be Used or Disclosed. My (My child's) health information that may be used or disclosed for this research may include my (my child's) medical records.

3. Who May Disclose My (My Child's) Health Information? During this study, the researcher and the researcher's staff may get my (my child's) health information from hospitals, clinics, and health care providers who have treated me.

4. Who May Receive My (My Child's) Health Information? The health information disclosed by researchers and information given by me during the research study may be received and used by Greg Armstrong, M.D., M.S.C.E., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Biorepository (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), and the LTFU Statistical Center (Seattle, WA).

5. Right to Refuse to Sign this Authorization. I do not have to sign this form. If I decide not to sign the form, I may not be allowed to take part in this study. However, my decision not to sign this form will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.

6. Right to Revoke. I can change my mind and revoke (take back) this authorization (permission) at any time by sending a written notice of my decision to Dr. Greg Armstrong, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105. If I take back my permission, the researcher may use and disclose only the protected health information already collected for the research study. No further health information about me will be collected by the researcher or disclosed to the researcher for this study.

7. Possible Re-disclosure. After my (my child's) health information is given out under this authorization form, there is a chance that it might be re-disclosed outside this study and no longer covered by this form. However, I understand that the research team and the St. Jude Institutional Review Board (IRB) are very careful to protect my (my child's) privacy and limit the use of information that can identify me (my child). (The IRB is the committee that reviews studies to be sure that the rights and safety of those taking part in the study are protected). In addition, the LTFU study maintains a Certificate of Confidentiality from the National Institute of Health to protect the identity of research subjects.

For those taking part in the research study who are not legal adults, this authorization form will expire when they become legal adults (unless the person taking part in the study has appointed a legal guardian to provided authorization). A new form will be required when the child becomes a legal adult. For a legal adult taking part in this study, this authorization (permission) expires at the end of the study.

I am the research participant, or I am legally authorized to act on behalf of the person taking part in the study.

I have read this information and have received a copy of the form.

! Sign Here

Printed name of research participant _____ Date of birth _____

Signature of research participant or legal guardian _____ Date _____ Fill in Date

Printed name of legal guardian _____

Describe how the person signing has authority to act on behalf of the research participant _____

[1] HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

Please! Do not mark below this line

4590023474

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.
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 Grape

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, calisthenics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No ☒ Yes

Example 2

2. Has your child ever taken. . .

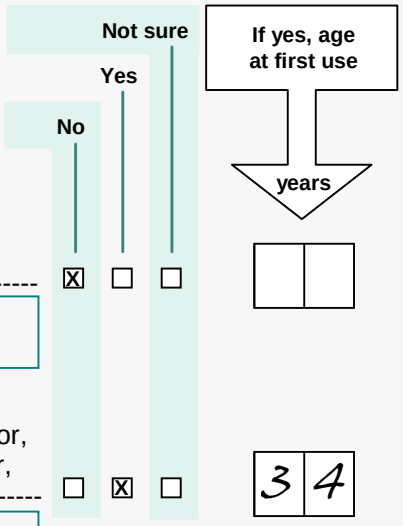
a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil----------

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

b. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES, such as Zocor, Pravachol, Lipitor, Colestid (colestipol), Tricor, Lescol, Lopid (gemfibrozil), Mevacor, niacin, or Lorelco----------

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

mevacor



Example 3

3. When was this condition diagnosed?

0 4 Month (mm)

1 9 9 5 Year (yyyy)

Please! Do not mark below this line

9868023477

A1. What is your child's date of birth?

☐☐ / ☐☐ / ☐☐☐☐
m m d d y y y y

A2. What is his/her sex?

☐ Male

☐ Female

A3. To the nearest inch, what is his/her current height without shoes?

☐ feet, and ☐☐ inches

A4. To the nearest pound, what is his/her current weight without shoes?

☐☐☐ pounds

A5. To which one of the following groups does he/she belong?

☐ White

☐ Black

☐ American Indian or Alaskan Native

☐ Asian

☐ Pacific Islander

☐ Other

Specify

A5a. Is he/she Hispanic?

☐ No

☐ Yes

A6. Is he/she a twin or born of a multiple birth?

☐ No → *Go to Question A7.*

☐ Yes

A6a. If yes, which type of multiple is he/she?

☐ Identical twin

☐ Fraternal (non-identical) twin, same sex

☐ Fraternal (non-identical) twin, opposite sex

☐ Not sure what type of twin, same sex

☐ More than twin

Specify

A7. Was this child adopted?

☐ No

☐ Yes

A8. Concerning your child's current residence, does he/she:

☐ Own a residence

☐ Rent

☐ Live with parents

☐ Other

Specify

A9. On average, how many times per week does your child use the internet?

☐ Never

☐ 1-10 times

☐ 11 or more times

Medical Care

The next questions are about health care received by your child during the 2 year period between May 2012 and May 2014.

B1. Between May 2012 and May 2014, which of the following health care providers (excluding dentists) did your child see or talk to for medical care? *(Mark all that apply)*

- ☐ None → *Go to Question B6.*
- ☐ Physician (including Osteopath)
- ☐ Nurse
- ☐ Chiropractor
- ☐ Physical Therapist
- ☐ Psychologist or psychiatrist
- ☐ Other

Specify

B2. Where did your child receive his/her health care? *(Mark all that apply)*

- ☐ Doctor's office
- ☐ Oncology (cancer) center or clinic
- ☐ Other type of clinic
- ☐ Hospital
- ☐ Emergency Room or Urgent Care Center
- ☐ Long-term follow-up clinic
- ☐ Other

Specify

B3. During this 2 year period, how many times did your child see a physician?

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

B4. During this 2 year period, how often did you telephone a doctor's office regarding an illness or a medical condition your child may have had?

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

B5. During this 2 year period, how many times was he/she admitted to any hospital?

☐☐

B6. At the present time, does your child have any of the following?

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

Specify

Please! Do not mark below this line

B7. Please indicate all medicines/drugs your child took *regularly* during the two-year period between May 2012 and May 2014.

- **We are only asking about medicines/drugs which 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 were 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 any of these? No	If yes, is he/she currently taking any of these? 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						
5. MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						

B7. (Cont.) Please indicate all medicines/drugs your child took *regularly* during the two-year period between May 2012 and May 2014.

- We are only asking about medicines/drugs which 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 were 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 any of these? No	If yes, is he/she currently taking any of these? Yes
6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor, Zetia, Tricor, Vytorin, gemfibrozil----------	☐	☐	☐	☐☐ years	☐	☐
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						
9. MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone, Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil----------	☐	☐	☐	☐☐	☐	☐
If yes, specify the name of the drug(s) or indicate you do not know the specific name						
10. 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

Medical Conditions

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

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. In addition, please give your child's approximate age when the condition first occurred. (If more than one occurrence, please give age at first occurrence.)

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

HEARING/VISION/SPEECH

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

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
C1. Hearing loss requiring a hearing aid?	☐	☐	☐	☐	☐☐
C2. Deafness in both ears not completely corrected by hearing aid?	☐	☐	☐	☐	☐☐
C3. Deafness in only one ear not completely corrected by hearing aid?	☐	☐	☐	☐	☐☐
C4. Tinnitus or ringing in the ears?	☐	☐	☐	☐	☐☐
C5. Persistent dizziness or vertigo?	☐	☐	☐	☐	☐☐
C6. Hearing loss, not requiring a hearing aid?	☐	☐	☐	☐	☐☐
C7. Any other hearing problems?	☐	☐	☐	☐	☐☐

If yes, describe this problem.

	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)
C8. Legally blind in only one eye?	☐	☐	☐	☐	☐☐

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

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

	No	Yes, but the condition is no longer present	Yes, and the condition is still present	Not sure	If yes, age at first occurrence (years)
C9. Legally blind in both eyes?	☐	☐	☐	☐	☐☐
C10. Cataracts?	☐	☐	☐	☐	☐☐
C11. Glaucoma (excess pressure in the eyeball)?	☐	☐	☐	☐	☐☐
C12. Problems with double vision?	☐	☐	☐	☐	☐☐
C13. A detached retina or any other condition of the retina?	☐	☐	☐	☐	☐☐

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

If yes, describe this problem.

	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)
C14. Crossed or turned eyes (strabismus)?	☐	☐	☐	☐	☐☐
C15. Lazy eye (amblyopia)?	☐	☐	☐	☐	☐☐
C16. Any other trouble seeing with one or both eyes even when wearing glasses?	☐	☐	☐	☐	☐☐
C17. Very dry eyes requiring eye drops or ointment?	☐	☐	☐	☐	☐☐
C18. Any other eye problems?	☐	☐	☐	☐	☐☐

If yes, describe this problem.

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)
C19. Stammering or stuttering?	☐	☐	☐	☐	
C20. Any other speech defects?	☐	☐	☐	☐	

If yes, describe this defect.

C21. Abnormal sense of taste?	☐	☐	☐	☐	
C22. Loss of taste or smell lasting for 3 months or more?	☐	☐	☐	☐	

URINARY SYSTEM

D1. Kidney stones?	☐	☐	☐	☐	
D2. REPEATED (more than 3 in any 12 month period) kidney or bladder infections?	☐	☐	☐	☐	
D3. Dialysis?	☐	☐	☐	☐	
D4. Blood in his/her urine?	☐	☐	☐	☐	
D5. Urinary incontinence?	☐	☐	☐	☐	
D6. Any other kind of kidney, bladder or urinary tract disorder?	☐	☐	☐	☐	

If yes, describe this disorder.

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)
E1. An overactive thyroid gland (hyperthyroid)?	☐	☐	☐	☐	
E2. An underactive thyroid gland (hypothyroid)?	☐	☐	☐	☐	
E3. Thyroid nodules?	☐	☐	☐	☐	
E4. Swollen or enlarged thyroid gland?	☐	☐	☐	☐	
E5. Diabetes that can be controlled with diet?	☐	☐	☐	☐	
E6. Diabetes controlled with pills or tablets?	☐	☐	☐	☐	
E7. Diabetes controlled with insulin shots?	☐	☐	☐	☐	
E8. Deficiency of growth hormone?	☐	☐	☐	☐	
E9. Has your child received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?	☐	☐	☐	☐	
E10. Osteoporosis or osteopenia (thin, brittle, or fragile bones)?	☐	☐	☐	☐	
E11. Has your child ever broken a bone?	☐	☐	☐	☐	

If yes, describe <u>all</u> occurrences.

E12. Any other hormonal problems?	☐	☐	☐	☐	

If yes, describe this problem.

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.

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	Not sure	If yes, age at first occurrence (years)
F1. Congestive heart failure or cardiomyopathy (weak heart muscle)?	☐	☐	☐	☐	
F2. A myocardial infarction (heart attack)?	☐	☐	☐	☐	
F3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor?	☐	☐	☐	☐	
F4. Coronary heart disease?	☐	☐	☐	☐	

If yes, describe this problem.

F5. Hypertension (high blood pressure) requiring medication?	☐	☐	☐	☐	

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

F6. Angina pectoris (chest pains due to lack of oxygen to the heart requiring medication such as nitroglycerin)?	☐	☐	☐	☐	
F7. Pericarditis or fluid around the heart?	☐	☐	☐	☐	
F8. Pericardial constriction (scarring or tightness of the sac around the heart)?	☐	☐	☐	☐	
F9. Stiff or leaking heart valves?	☐	☐	☐	☐	
F10. Blood clot in head, lung, arm, leg, or pelvis?	☐	☐	☐	☐	
F11. 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)
F12. High cholesterol (or triglyceride) requiring prescription medication?	☐	☐	☐	☐	

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

F13. Any other heart or circulatory problems?	☐	☐	☐	☐	

If yes, describe this problem.

F14. Has anyone in your child's immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55?
☐ No ☐ Yes

RESPIRATORY SYSTEM

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

G1. Asthma?	☐	☐	☐	☐	
G2. Chronic cough or shortness of breath for more than one month?	☐	☐	☐	☐	
G3. Has your child had a need for extra oxygen?	☐	☐	☐	☐	
G4. Pneumonia, 3 or more times in the past 2 years?	☐	☐	☐	☐	
G5. Emphysema?	☐	☐	☐	☐	
G6. Lung fibrosis or "scarring" of the lung?	☐	☐	☐	☐	
G7. Problems with breathing while at rest that lasted for more than 3 months?	☐	☐	☐	☐	

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.

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)
G8. Any other breathing or lung problems?	☐	☐	☐	☐	

If yes, describe this problem.

DIGESTIVE SYSTEM

	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)
H1. Hepatitis?	☐	☐	☐	☐	

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

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

H2. Cirrhosis of the liver?	☐	☐	☐	☐	
H3. Any other liver trouble?	☐	☐	☐	☐	

If yes, describe.

H4. Intestinal (colon) polyps?	☐	☐	☐	☐	
H5. Fatty liver?	☐	☐	☐	☐	
H6. Esophageal strictures (narrowing of the esophagus)?	☐	☐	☐	☐	
H7. Rectal or anal fistula?	☐	☐	☐	☐	
H8. Rectal or anal stricture (narrowing or scarring)?	☐	☐	☐	☐	
H9. Any other stomach or digestive trouble?	☐	☐	☐	☐	

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)
I1. Amputation of an arm, leg, hand, foot?	☐	☐	☐	

If yes, specify (example: left hand, right foot).

I2. Scoliosis surgery (insertion of rods or other methods to straighten the spine)?	☐	☐	☐	
I3. Other surgery of spinal cord or spine?	☐	☐	☐	

If yes, specify.

I4. Leg lengthening or shortening procedures?	☐	☐	☐	
I5. Joint replacement?	☐	☐	☐	

If yes, specify.

I6. Other bone surgery?	☐	☐	☐	

If yes, specify.

I7. Coronary artery bypass surgery?	☐	☐	☐	
I8. Pericardiectomy (stripping of the sac around the heart)?	☐	☐	☐	

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)
I9. Heart catheterization ("heart cath")?	☐	☐	☐	
I10. Angioplasty (enlarging a heart vessel using a balloon)?	☐	☐	☐	
I11. Surgery for heart valve replacement?	☐	☐	☐	
I12. Surgery for pacemaker?	☐	☐	☐	
I13. Other heart surgery?	☐	☐	☐	

If yes, specify.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I14. Surgery for intestinal obstruction (blocked intestines)?	☐	☐	☐	
I15. Colostomy or ileostomy (stool going into a bag)?	☐	☐	☐	
I16. Biopsy or removal of lump in thyroid gland?	☐	☐	☐	
I17. Removal of part or all of the thyroid gland?	☐	☐	☐	
I18. Removal of the spleen?	☐	☐	☐	
I19. Ventriculoperitoneal (VP) shunt (tube from the brain to the abdomen under the skin) that removes excess spinal fluid?	☐	☐	☐	
I20. Breast biopsy?	☐	☐	☐	
I21. Breast-conserving or breast-sparing surgery (lumpectomy)?	☐	☐	☐	
I22. Mastectomy or removal of a breast?	☐	☐	☐	

If yes, was one or both breasts removed?
☐ One ☐ Both

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)
I23. Any lung surgery?	☐	☐	☐	

If yes, specify.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I24. Periodontal (gum) surgery?	☐	☐	☐	
I25. Heart transplant?	☐	☐	☐	
I26. Lung transplant?	☐	☐	☐	
I27. Kidney transplant?	☐	☐	☐	
I28. Liver transplant?	☐	☐	☐	
I29. Bone marrow transplant?	☐	☐	☐	
I30. Other organ transplant?	☐	☐	☐	

If yes, specify transplant.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I31. Cataract surgery?	☐	☐	☐	

Males → Go to Question I35.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I32. Removal of one ovary?	☐	☐	☐	
I33. Removal of both ovaries?	☐	☐	☐	
I34. Removal of uterus?	☐	☐	☐	

Females → Go to Question I37.

	No	Yes	Not sure	If yes, age at first occurrence (years)
I35. Removal of one testis?	☐	☐	☐	
I36. Removal of both testes?	☐	☐	☐	
I37. Any other surgery?	☐	☐	☐	

If yes, specify surgery.

Please! Do not mark below this line

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

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)
J1. Problems with learning or memory?	☐	☐	☐	☐	

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

- ☐ Mild; does not interfere with my child's work, school, or general life. He/she does/did not need special help in school.
- ☐ Moderate; interferes with my child's work, school, or general life, but he/she is capable of independent living. He/she uses/used special help in school.
- ☐ Severe; My child is significantly impaired in his/her school or work performance or in his/her 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 he/she is living in an institution for people with disabling conditions.

J2. Epilepsy, repeated seizures, convulsions, or blackouts?	☐	☐	☐	☐	

If yes, describe this problem and list medications.

If yes, is your child currently taking medication for this?
☐ No ☐ Yes

J3. Migraine?	☐	☐	☐	☐	

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)
J4. Other severe headaches?	☐	☐	☐	☐	

If yes, list medications if required to control.

J5. 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 my child's walking and daily routine.
- ☐ Disabling; My child requires a wheelchair or cannot walk because of this problem.

J6. Tremors or problems with movements?	☐	☐	☐	☐	
J7. Problems chewing or swallowing solids or liquids?	☐	☐	☐	☐	
J8. Decreased sense of touch or feeling in hands, fingers, arms or legs?	☐	☐	☐	☐	
J9. Prolonged pain in arms, legs or back?	☐	☐	☐	☐	
J10. Abnormal sensation in arms, legs or back?	☐	☐	☐	☐	
J11. Weakness or inability to move arm(s)?	☐	☐	☐	☐	

Please! Do not mark below this line

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

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)
J12. Weakness or inability to move leg(s)?	☐	☐	☐	☐	
J13. Paralysis of any kind?	☐	☐	☐	☐	
J14. Has your child had a stroke?	☐	☐	☐	☐	
If yes, as a result of the stroke . . .					
a. Did the symptoms last more than 24 hours? ☐ No ☐ Yes					
b. Did it affect:					
Speech	☐	☐	☐	☐	
Only one side of the body	☐	☐	☐	☐	
Both sides of the body	☐	☐	☐	☐	
c. Did your child lose consciousness? ☐ No ☐ Yes					
d. Did he/she have weakness or inability to move arm(s)?	☐	☐	☐	☐	
e. Did he/she have weakness or inability to move leg(s)?	☐	☐	☐	☐	
f. Did he/she have paralysis of any kind?	☐	☐	☐	☐	

If yes, describe this problem.

J15. Any other brain or nervous system problems?	☐	☐	☐	☐	

If yes, describe this problem.

SOCIAL FUNCTIONING

K1. About how many close friends does your child have?

- ☐ 0 → *Go to Question K3.*
- ☐ 1
- ☐ 2 or 3
- ☐ 4 or more

K2. About how many times a week does your child do things with close friends?

- ☐ Less than 1
- ☐ 1 or 2
- ☐ 3 or more

K3. Compared to other children of his/her age, how well does your child . . .

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

K4. How well do the following statements describe your child's behavior?

	Often True	Sometimes True	Not True
a. Has sudden changes in mood or feelings	☐	☐	☐
b. Feels or complains that no one loves him/her	☐	☐	☐
c. Is rather high strung, tense, or nervous	☐	☐	☐
d. Cheats or tells lies	☐	☐	☐
e. Is too fearful or anxious	☐	☐	☐
f. Argues too much	☐	☐	☐
g. Has difficulty concentrating, cannot pay attention for long	☐	☐	☐
h. Is easily confused, seems to be in a fog	☐	☐	☐
i. Bullies, or is cruel or mean to others	☐	☐	☐
j. Is disobedient at home	☐	☐	☐
k. Is disobedient at school	☐	☐	☐
l. Does not seem to feel sorry after he/she misbehaves	☐	☐	☐

K4. (Cont.) How well do the following statements describe your child's behavior?

	Not True	Sometimes True	Often True
m. Has trouble getting along with other children	☐	☐	☐
n. Has trouble getting along with teachers	☐	☐	☐
o. Is impulsive, or acts without thinking.	☐	☐	☐
p. Feels worthless or inferior	☐	☐	☐
q. Is not liked by other children	☐	☐	☐
r. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions	☐	☐	☐
s. Is restless or overly active, cannot sit still	☐	☐	☐
t. Is stubborn, sullen, or irritable	☐	☐	☐
u. Has a very strong temper and loses it easily	☐	☐	☐
v. Is unhappy, sad or depressed	☐	☐	☐
w. Is withdrawn, does not get involved with others	☐	☐	☐

If child is 12 years of age or older → *Go to Question K6.*

K5. FOR CHILDREN UNDER 12 YEARS OF AGE

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

If child is under 12 years of age → *Go to Question K7.*

K6. FOR CHILDREN 12 YEARS OF AGE OR OLDER

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

K7. How much <u>bodily</u> pain has your child had during the <u>past 4 weeks</u>?

- ☐ None → *Go to Question L1, next page.*
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

K8. During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your child's normal work (including both work outside the home and housework)?

- ☐ Not at all
- ☐ A little bit
- ☐ Moderately
- ☐ Quite a bit
- ☐ Extremely

K9. For pain that your child has had during the <u>past 4 weeks</u>, where has this pain been located? ***(Mark all that apply)***

- ☐ Head
- ☐ Neck
- ☐ Chest
- ☐ Hands/Arms
- ☐ Abdomen
- ☐ Back
- ☐ Pelvis
- ☐ Legs/Feet
- ☐ Other

Specify

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMOR

The following questions (L1-L9) relate to whether your child has ever been diagnosed with cancer, leukemia, tumor or other similar illness.

L1. Has your child ever been diagnosed with cancer, leukemia, tumor, or similar illness?

☐ No → *Go to Question M1.*

☐ Yes

L2. Please write the name of this disease.

L3. Did he/she have treatment for this disease?

☐ No → *Skip L3a and go to Question L4.*

☐ Yes → **L3a. What treatments did he/she receive? *(Mark all that apply)***

- ☐ Chemotherapy
- ☐ Radiation therapy
- ☐ Surgery

L4. Where was this diagnosed?

Hospital:
Address:
City, State/Province, Zip Code:
Doctor's Name:

Date of Diagnosis:

Month		**Year**		

L5. Has your child had any additional cancers, leukemias, tumors, or similar illnesses after this diagnosis? (Include any relapse or recurrence of his/her original diagnosis.)

☐ No → *Go to Question M1.*

☐ Yes

L6. Please write the name of this disease.

L7. Did he/she have treatment for this disease?

☐ No → *Skip L7a and go to Question L8.*

☐ Yes → **L7a. What treatments did he/she receive? *(Mark all that apply)***

- ☐ Chemotherapy
- ☐ Radiation therapy
- ☐ Surgery

L8. Where was this diagnosed?

Hospital:
Address:
City, State/Province, Zip Code:
Doctor's Name:

L9. Was this a:

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

Date of Recurrence or New Diagnosis:

Month		**Year**		

Please use a separate sheet of paper for additional cancers

Please! Do not mark below this line

MARITAL STATUS

M1. What is your child's current living arrangement? *(Mark all that apply)*

- ☐ Lives with spouse/partner
- ☐ Lives with parent(s)
- ☐ Lives with roommate(s)
- ☐ Lives with brother(s) and/or sister(s)
- ☐ Lives with other relative(s) (not including minor children)
- ☐ Lives alone
- ☐ Other

Specify

M2. Has your child ever been married or had a live-in relationship (lived as married)?

- ☐ No → *Go to Question N1.*
- ☐ Yes

M3. Which of these possibilities best describes his/her <u>current</u> marital status?

- ☐ Married
- ☐ Living with a partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

M4. How many times has he/she been married or lived as married?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9+

OFFSPRING/PREGNANCY HISTORY

N1. To your knowledge, has your child ever been sexually active (had sexual intercourse)?

- ☐ Don't know
- ☐ No → *Go to Question O1.*
- ☐ Yes

N2. Is he/she currently sexually active?

- ☐ Don't know
- ☐ No
- ☐ Yes

N3. Is your daughter currently pregnant, or does your son currently have a woman pregnant by him?

- ☐ Don't know
- ☐ No
- ☐ Yes

N4. Was there ever a period in your child's life when he/she and a partner tried for one year or more to become pregnant, without success?

- ☐ Don't know
- ☐ No
- ☐ Yes

N5. Has your daughter ever become pregnant, or has your son ever had a woman become pregnant by him?

- ☐ Don't know
- ☐ No → *Go to Question O1.*
- ☐ Yes

N6. Including live births, stillbirths, miscarriages, and abortions, how many times has your daughter become pregnant or has your son had a woman become pregnant by him?

☐☐ **times**

Please! Do not mark below this line

N7. Please fill in the following information for each of your daughter's pregnancies, or each time a woman has become pregnant by your son, regardless of the outcome.

	Pregnancy outcome				Your child's age at start of pregnancy	Partner's age at start of pregnancy	Weeks pregnancy lasted
	Live birth	Stillbirth	Miscarriage	Medical abortion			
Pregnancy 1. .	☐	☐	☐	☐			
Pregnancy 2. .	☐	☐	☐	☐			
Pregnancy 3. .	☐	☐	☐	☐			
Pregnancy 4. .	☐	☐	☐	☐			
Pregnancy 5. .	☐	☐	☐	☐			

Please attach a separate sheet of paper if more than 5 pregnancies

HEALTH HABITS

Physical Activity

O1. On how many of the past 7 days did your child exercise or do sports for at least 20 minutes that made him/her sweat or breathe hard (e.g., dancing, jogging, basketball, etc.)?

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

O2. Because of any impairment or health problems, does your child need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around their home?

- ☐ No
- ☐ Yes

O3. Because of any impairment or health problems, does your child need the help of other persons in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- ☐ No
- ☐ Yes

O4. Does any impairment or health problem keep your child from holding a job or attending school?

- ☐ No
- ☐ Yes

O5. Does he/she currently have a driver's license?

- ☐ No
- ☐ Yes

O6. Over the last 2 years, how long (if at all) has your child's health limited him/her in each of the following activities?
(Mark one box for each item.)

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

Health Practices

O7. In general, would you say your child's health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

O8. Would you rate your child as being:

- ☐ Completely disabled
- ☐ Severely disabled
- ☐ Moderately disabled
- ☐ Mildly disabled
- ☐ Not at all disabled

O9. Some people get a general physical examination from a doctor once in a while even though they are feeling well and have not been sick. When was the last time your child had a general physical examination when he/she was not sick?

- ☐ 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
- ☐ Don't know

O10. When was the last time your child had an echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves)?

- ☐ 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
- ☐ Don't know

O11. When was the last time your child had a test to measure his/her bone strength or bone mineral density (such as a DEXA, quantitative CT scan, or ultrasound)?

- ☐ 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
- ☐ Don't know

O12. How long has it been since your child last went to a dentist?

- ☐ 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
- ☐ Don't know

GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions. 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.

P1a. 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. Any other genetic disorder	☐	☐	☐

If yes, describe this disorder.

P1b. If your child has a son or daughter (blood relative only), has he/she ever had any of the above conditons? ***(Mark all that apply)***

My child's . . .	***What conditions?***
☐ Son →	
☐ Daughter →	

Please! Do not mark below this line

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.

P2. Has your child ever had genetic counseling for cancer risk?

☐ No

☐ Yes

P3a. 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.

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

If other, please specify.

P3b. If your child has a son or daughter (blood relative only), has he/she ever had any of the conditions in Question P3a? *(Mark all that apply)*

My child's . . . ***What conditions?***

☐ Son →

☐ Daughter →

P4. If your child has a son or daughter (blood relative only), has he/she ever had cancer? *(Mark all that apply)*

My child's . . . ***What types?***

☐ Son →

☐ Daughter →

SCHOOL HISTORY

Q1. What is the highest grade or level of schooling that your child has completed?

☐ 1 - 8 years (grade school)

☐ 9 - 12 years (high school), but did not graduate

☐ Completed high school/GED

☐ Training after high school, other than college

☐ Some college

☐ Other

Specify

Q2. If your child has completed high school, did he/she receive a regular high school diploma or did he/she receive a high school equivalency certificate, also called a GED?

☐ High school diploma

☐ GED

Please! Do not mark below this line

Q3. In elementary, junior, or high school was he/she ever in any of the following programs? *(Mark all that apply)*

	No	Yes	Not sure
Learning disabled or special education program?	☐	☐	☐
If yes, was he/she in the program because of. . .			
a. Missed school	☐	☐	☐
b. Low scores on tests	☐	☐	☐
c. Problems learning or concentrating	☐	☐	☐
d. Emotional or behavioral problems	☐	☐	☐
Advanced placement or talented program?	☐	☐	☐
Homebound education for at least one school year?	☐	☐	☐

Q4. If your child was in a learning disabled or special education program, what grades was he/she in at that time? *(Mark all that apply)*

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

EMPLOYMENT HISTORY

R1. Has your child ever had a job?

- ☐ No → *Go to Question S1.*
- ☐ Yes

R2. What is his/her current employment status? Include unpaid work in the family business or farm. *(Mark all that apply)*

- ☐ Not currently working → *Go to Question S1.*
- ☐ Working full-time (30 or more hours per week)
- ☐ Working part-time (less than 30 hours per week)
- ☐ Caring for home or family (not seeking paid work)
- ☐ Unemployed and looking for work
- ☐ Unable to work due to illness or disability
- ☐ Student
- ☐ Other

Specify.

R3. The following questions are about your child's present occupation. Please write his/her job title and brief details of what he/she does. If he/she has more than one job, please give the title of <u>your child's main job (please give only one)</u>:

R3a. Main job title:

R3b. Please briefly describe your child's primary job tasks:

INCOME

S1. Over the last year, what was the total income of the household your child lives in?

- ☐ Less than $20,000
- ☐ $20,000 - $39,999
- ☐ $40,000 - $59,999
- ☐ $60,000 - $79,999
- ☐ $80,000 - $99,999
- ☐ Over $100,000

S2. During the past year, how many people in this household were supported on this income?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9 or more

INSURANCE

T1. Have you ever had difficulty obtaining health insurance for your child because of his/her health history?

- ☐ No
- ☐ Yes

T2. Does your child currently have health insurance coverage?

- ☐ Canadian resident → *Go to Question T4.*
- ☐ No → *Go to Question T4.*
- ☐ Yes

T3. How is this insurance provided? *(Mark all that apply)*

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

Specify.

T3a. Does this health insurance plan have any exclusions or restrictions because of your child's health history?

- ☐ Don't know
- ☐ No
- ☐ Yes

Specify.

T3b. Is there an extra premium charge on your health insurance policy because of your child's health history?

- ☐ Don't know
- ☐ No
- ☐ Yes

Please! Do not mark below this line

T4. Have you ever had difficulty obtaining life insurance for your child because of his/her health history?

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

T5. Does your child currently have life insurance coverage?

- ☐ No
- ☐ Yes

OTHER ISSUES

Please rate how concerned you are about the following:

	Not at all concerned	Not very concerned	Concerned	Somewhat concerned	Very concerned
U1. Your child's future health	☐	☐	☐	☐	☐
U2. Your child's ability to have children	☐	☐	☐	☐	☐
U3. Your child developing a cancer	☐	☐	☐	☐	☐
U4. Your ability to get health insurance for your child	☐	☐	☐	☐	☐
U5. Your ability to get life insurance for your child	☐	☐	☐	☐	☐
U6. Any other issues	☐	☐	☐	☐	☐

Please specify.

Continue on next page.

We have your child's current address and phone as:

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

☐ Correct ☐ Not correct ☐ Moving

Do you have an email address we could use to contact you?

☐ No ☐ Yes

Your Email Address

Please give us your child's correct address or location (if different from above) and cell phone number if applicable:

Address		
City	State	
Zip Code	Home Phone Number	Cell Phone Number

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 you
City	State
Zip Code	Phone Number

When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

LONG-TERM FOLLOW-UP STUDY
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

Thank you!

Please! Do not mark below this line