LTFU

Long-Term Follow-Up Study

STROKE SURVEY

St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
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 Memorial Hospital
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
The Denver 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:
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Memphis, TN 38105-3678

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

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

Dear <Proxy name>,

We are writing to you with regard to <participant's name>'s participation in the Long-Term Follow-Up Study (LTFU). We share in your loss of <participant's name>. Our goal is to improve the treatment of childhood cancer and maximize the health of cancer survivors. To accomplish this goal, in 1994 we established the LTFU Study with 26 participating cancer centers from around the United States and Canada.

On a previous study questionnaire we learned that <participant's name> may have had a stroke. We are contacting you to learn more about the nature and severity of stroke-related problems that have been reported by study participants.

We ask that you please complete this brief questionnaire and return it to us in the enclosed postage-paid envelope within 2 weeks. If you prefer, you can complete the questionnaire online at www.stjude.org/strokesurveyproxy. Your user ID is <randcode> and your password is <participant's name>'s date of birth. If you need any assistance, please call us at 1-800-775-2167 or email us at LTFU@stjude.org.

Your participation is voluntary. All information collected for this study is confidential and you can be assured that we will respect <participant's name>'s and your privacy at all times. Names or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

We would like to thank you, on <participant's name>'s behalf, for the information which you've already shared and will hopefully share in the near future. While your and <participant's name>'s information will always remain private, your efforts are appreciated by past, present, and future survivors everywhere.

With our sincerest gratitude,

Leslie L. Robison, Ph.D.
Principal Investigator, Long Term Follow-Up Study
Director, Epidemiology and Cancer Control
St. Jude Children's Research Hospital

Please! Do not mark below this line

Person completing this questionnaire is:

_____

(Print your full name)

Please specify your relationship to <participant>:

_____

A. CONFIRMATION OF FIRST STROKE

A stroke is when a part of the brain is injured because a blood vessel to the brain is either blocked or bursts. When that happens, part of the brain cannot receive oxygen or nutrients. There are 2 types of stroke: ischemic stroke, when blood flow to the brain is blocked; and hemorrhagic stroke, when a blood vessel in the brain ruptures, causing bleeding into the brain. Signs of a stroke can include: weakness or numbness on one side of the body, drooping of one side of the face, difficulty speaking, or problems with balance. Sometimes you do not have any symptoms of a stroke.

Our records show that <participant name> reported having a stroke at age (<strokeage>).

Can you confirm that he/she had a stroke?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***STOP! END OF SURVEY. Thank you for your participation.***

Is this age correct?

- ☐ Yes
- ☐ No → **Please give correct age:** ☐☐ years

B. FIRST STROKE

We would like to ask you more details about the first stroke that he/she had.

1) Did he/she have any sort of test at the time of the stroke, for example:

	Yes	No	Don't know
a. CT Scan (CAT Scan)? . .	☐	☐	☐
b. MRI?	☐	☐	☐

c. ***IF YES,*** did the imaging confirm the stroke?

☐ Yes ☐ No ☐ Don't know

2) Did he/she have bleeding into the brain (hemorrhagic stroke)?

☐ Yes ☐ No ☐ Don't know

3) Or did he/she have a blockage of blood to the brain (ischemic stroke)?

☐ Yes ☐ No ☐ Don't know

4) Did he/she have any of the following symptoms? ***(Check all that apply)***

- ☐ weakness on only one side of the body
- ☐ weakness on both sides of the body
- ☐ difficulty speaking
- ☐ difficulty walking
- ☐ dizziness where it seems like the room is spinning, or the floor is moving
- ☐ numbness, on only one side of the body
- ☐ numbness, on both sides of the body
- ☐ seizure/convulsion
- ☐ headache
- ☐ any change in vision, such as double vision

5) If he/she had symptoms, did any of these symptoms last for greater than 24 hours?

- ☐ Yes
- ☐ No
- ☐ Don't know

6) Did he/she receive any medical treatment for their stroke while in the hospital?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***Please skip to Question 7.***

IF YES, **were they given…** ***(Check all that apply)***

- ☐ aspirin or plavix
- ☐ heparin, lovenox, enoxaparin, coumadin or warfarin
- ☐ blood thinner but you do not remember the name

Please! Do not mark below this line

7) Did he/she receive any medical treatment for the stroke at home (after discharge from the hospital)?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ *Please skip to Question 8.*

IF YES, were they given… ***(Check all that apply)***

- ☐ aspirin or plavix
- ☐ heparin, lovenox, enoxaparin, coumadin or warfarin
- ☐ blood thinner but you do not remember the name

8) Did they recover from the stroke?

- ☐ complete recovery
- ☐ partial recovery
- ☐ no recovery
- ☐ don't know

9) Do you think the stroke affected their quality of life?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ *Please skip to Question 10.*

IF YES, did it affect them

- ☐ "somewhat"?
- ☐ "a lot"?

C. GENERAL QUESTIONS

10) Did he/she have moyamoya (a condition of narrowing of blood vessels to the brain)?

- ☐ Yes → **Do you know the age when they were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

11) Did he/she have narrowing of blood vessels to the brain other than moyamoya?

- ☐ Yes → **Do you know the age when they were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

12) Did he/she have abnormal vessels in their brain?

- ☐ Yes → **Do you know the age when they were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

13) Did he/she have a diagnosis of neurofibromatosis type I (NF-I)?

- ☐ Yes
- ☐ No
- ☐ Don't know

D. ADDITIONAL STROKES

We would now like to ask about any recurrent strokes.

14) Did he/she have a second stroke?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***STOP! END OF SURVEY. Thank you for your participation.***

15) How old were they when they had the second stroke?

☐☐ years

16) Did he/she have any sort of test at the time of the second stroke, for example:

	Yes	No	Don't know
a. CT Scan (CAT Scan)? . .	☐	☐	☐
b. MRI?	☐	☐	☐

17) Did he/she have bleeding into the brain (<u>hemorrhagic stroke</u>)?

- ☐ Yes
- ☐ No
- ☐ Don't know

18) Or did he/she have a blockage of blood to the brain (<u>ischemic stroke</u>)?

- ☐ Yes
- ☐ No
- ☐ Don't know

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19) Did he/she have any of the following symptoms? ***(Check all that apply)***

- ☐ weakness on only one side of the body
- ☐ weakness on both sides of the body
- ☐ difficulty speaking
- ☐ difficulty walking
- ☐ dizziness where it seems like the room is spinning, or the floor is moving
- ☐ numbness, on only one side of the body
- ☐ numbness, on both sides of the body
- ☐ seizure/convulsion
- ☐ headache
- ☐ any change in vision, such as double vision

20) If they had symptoms, did any last for greater than 24 hours?

- ☐ Yes
- ☐ No
- ☐ Don't know

21) Were they taking any blood thinners at the time of the second stroke?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***Please skip to Question 22.***

IF YES, were they taking… ***(Check all that apply)***

- ☐ aspirin or plavix
- ☐ heparin, lovenox, enoxaparin, coumadin or warfarin
- ☐ blood thinner but you do not remember the name

22) Did they recover from the second stroke?

- ☐ complete recovery
- ☐ partial recovery
- ☐ no recovery
- ☐ don't know

23) How many strokes do you believe he/she had in total?

☐☐

24) Do you think that the strokes affected their quality of life?

- ☐ Yes
- ☐ No
- ☐ Don't know

IF YES, did it affect them

- ☐ "somewhat"?
- ☐ "a lot"?

Thank you for completing this questionnaire and helping us better provide health information to cancer survivors. Please return this questionnaire in the self-addressed stamped envelope enclosed.

Thank You!

Please! Do not mark below this line