LTFU

Long-Term Follow-Up Study

STROKE 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

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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

Dear ,

Thank you for your continued participation in the Long-Term Follow-Up (LTFU) study. On a previous LTFU questionnaire, you indicated that you possibly experienced a stroke. We would like your help in understanding the nature and severity of stroke-related problems that have been reported by participants. Your answers could help us to develop guidelines for monitoring or treating future survivors at risk for stroke.

We are asking you to complete this questionnaire that will take approximately 10-15 minutes. You can leave any question blank that you are uncomfortable answering. Please complete the enclosed paper survey and return by mail in the provided envelope.

If you prefer, you can complete the questionnaire online at www.stjude.org/strokesurvey. Your user ID is and your password is your date of birth.

If you have any questions regarding this request, please call our office toll free at 1-800-775-2167. As always, any information you provide us will remain strictly confidential. Thank you again for your valuable contribution to this important study.

Sincerely,

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

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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.

Your questionnaire from SURVDATE indicated that you had a stroke at age STROKE1AGE.

Can you confirm that you've had a stroke?

- ☐ Yes
- ☐ No → ***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 you had.

1) Did you have any sort of test at the time of the stroke like 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 you have bleeding into the brain (hemorrhagic stroke)?

☐ Yes ☐ No ☐ Don't know

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

☐ Yes ☐ No ☐ Don't know

4) Did you 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 your vision, such as double vision

5) If you had symptoms, did any of your symptoms last for greater than 24 hours?

- ☐ Yes
- ☐ No
- ☐ Don't know

6) Did you receive any medical treatment for your stroke while in the hospital?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***Please skip to Question 7.***

IF YES, **did you receive…** ***(Check all that apply)***

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

7) Did you receive any medical treatment for your stroke at home (after discharge from the hospital)?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***Please skip to Question 8.***

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

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

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8) Did you recover from the stroke?

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

9) Do you feel that your stroke affected your quality of life?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ *Please skip to Question 10.*

IF YES, did it affect it

- ☐ "somewhat"?
- ☐ "a lot"?

C. GENERAL QUESTIONS

10) Radiation therapy as a treatment for cancer can injure normal blood vessels, sometimes many years later. Have you ever been told that you had radiation injury to a blood vessel(s) to the brain?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ *Please skip to Question 11.*

IF YES, did you ever receive any sort of treatment for this radiation injury? This might include: ***(Check all that apply)***

- ☐ steroid treatment (for example, prednisone or solumedrol)
- ☐ hyperbaric oxygen therapy
- ☐ aspirin
- ☐ other

If other, please specify:

11) Have you ever been told that you have moyamoya (a condition of narrowing of blood vessels to the brain)?

- ☐ Yes → **Please give age when you were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

12) Have you ever been told you have narrowing of your blood vessels to the brain other than moyamoya?

- ☐ Yes → **Please give age when you were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

13) Have you ever been told that the vessels in your brain are abnormal?

- ☐ Yes → **Please give age when you were first told:** ☐☐ years
- ☐ No
- ☐ Don't know

IF YES, **do you remember if there was a specific term used like for example:** ***(Check all that apply)***

- ☐ Cavernous malformation, also known as a "cav mal," "cavernous hemangioma," or "occult vascular malformation"?
- ☐ Arteriovenous malformation (AVM)?
- ☐ Stenosis?

14) Do you have a diagnosis of neurofibromatosis type I (NF-I)?

☐ Yes ☐ No ☐ Don't know

D. ADDITIONAL STROKES

We would now like to ask you about any recurrent strokes you may have had.

15) Did you have a second stroke?

- ☐ Yes
- ☐ No
- ☐ Don't know

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

16) How old were you when you had the second stroke?

☐☐ years

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17) Did you have any sort of test at the time of the second stroke like for example:

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

18) Did you have bleeding into the brain (hemorrhagic stroke)?

- ☐ Yes
- ☐ No
- ☐ Don't know

19) Or did you have a blockage of blood to the brain (ischemic stroke)?

- ☐ Yes
- ☐ No
- ☐ Don't know

20) Did you 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 your vision, such as double vision

21) If you had symptoms, did any of your symptoms last for greater than 24 hours?

- ☐ Yes
- ☐ No
- ☐ Don't know

22) Were you taking any blood thinners at the time of your second stroke?

- ☐ Yes
- ☐ No
- ☐ Don't know

→ ***Please skip to Question 23.***

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

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

23) Did you recover from the second stroke?

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

24) How many strokes do you believe you have had in total?

☐☐

25) Do you feel that your strokes affected your quality of life?

- ☐ Yes
- ☐ No
- ☐ Don't know

IF YES, did it affect it

- ☐ "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

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