

NOTE: THIS DOCUMENT CONTAINS INFORMATION ABOUT CONSENT FOR THE *STROKE SURVEY AND THE STROKE RESEARCH STUDIES REGISTRY* **ONLY**. ADDITIONAL INFORMATION AND CONSENT FOR PARTICIPATION IN A STUDY IS A SEPARATE PROCESS.

## UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, CONSENT TO BE CONTACTED FOR FUTURE RESEARCH

Study Title: An online pre-screening eligibility survey for the Stroke Research Studies Registry

You are being asked to complete the Stroke Survey because you have indicated that you are interested in finding out whether you might be a candidate for current or future research studies for stroke. By agreeing to take this survey, you will allow qualified professional study personnel at UCSF to add you to the Stroke Recovery Initiative's stroke registry and to contact you in the future to ask if you want to participate in stroke-related research studies. You have no obligation to actually participate in any study.

The investigator, Anthony S. Kim, MD, MAS, and the study personnel at the UCSF Department of Neurology have developed this Stroke Survey to help to determine whether people may be eligible to participate in current or future research studies of therapies for stroke. Examples of such interventions include studies of stem cells, physical therapy, electrical stimulation, or robotic therapy. We expect that up to 60,000 people will complete this Stroke Survey and an unknown number of participants may be enrolled in current and future stroke research studies.

The investigator and the study personnel have provided information on this website to explain the stroke registry and any available stroke research studies to you. If you have any questions about the registry, survey, or studies, you may contact the study personnel directly.

## What will happen if I complete this Stroke Survey?

If you agree to participate, you will be asked to go to a secure website (<http://redcap.ucsf.edu>) to complete the Stroke Survey online. The survey asks about your stroke and your medical history, including your medications. It will take about 30 minutes to complete.

We will review your responses and if you meet the initial eligibility criteria for a specific study, we may contact you by email to tell you more about that study and to conduct additional screening to help to determine whether you might be eligible for that specific research study.

We will also store your responses and may use these responses and your contact information to contact you about future research studies related to stroke. You may ask to remove yourself from future contact at any time by contacting us at 1-800-887-1624 or by email at [StrokeRecoveryInitiative@ucsf.edu](mailto:StrokeRecoveryInitiative@ucsf.edu).

Completing this Stroke Survey DOES NOT mean that you have agreed to take part in any research studies for stroke, but does mean that you agree to be contacted to determine whether you MAY be eligible for a study for stroke. There will be a separate enrollment and consent process for the actual research studies.

## Are there any risks to me or my privacy?

Some of the questions may make you feel uncomfortable or raise unpleasant memories. You are free to skip any question.

We will do our best to protect the information that we collect from you. The Stroke Survey will include details that directly identify you, such as your name, email address, and telephone number so that we can contact you after we review your responses. Information that identifies you will be kept secure to the degree permitted by the technology we use.

Only a small number of researchers will have direct access to survey responses. If a study based on these responses is published or presented at scientific meetings, names and other information that might identify you will not be used.

## Are there benefits?

There is no direct benefit to you. Your responses will be used for stroke research and you may be contacted about current or future research studies for stroke.

## Can I say "No"?

Yes; you do not have to complete this Stroke Survey and completing the survey is NOT required to participate in any research study. Choosing not to complete this survey will not have any effect on your current benefits or any current and future medical care from UCSF.

## Are there any payments or costs?

You will not be paid for completing the survey. There are no costs to you for completing this survey other than any data or Internet fees associated with accessing our website that you may incur from your Internet provider.

## Who can answer my questions about the Stroke Survey?

You can talk with the study personnel at UCSF about any questions, concerns, or complaints you have about this survey. Contact the UCSF study personnel at 1-800-887-1624 or [StrokeRecoveryInitiative@ucsf.edu](mailto:StrokeRecoveryInitiative@ucsf.edu).

If you wish to ask questions about this Stroke Survey or your rights as a research participant to someone other than the researchers, or if you wish to voice any problems or concerns you may have about the survey, please contact the UCSF Office of the Committee on Human Research at 415-476-1814.

Our study website (<http://StrokeRecoveryInitiative.ucsf.edu>) contains additional information about the registry and current studies for stroke. For future research studies, you will be provided with contact information for the specific research study if we contact you at a later date.

**PARTICIPATION IN RESEARCH IS VOLUNTARY.**