REGISTRY OF POTENTIAL STROKE RESEARCH STUDY PARTICIPANTS

We are interested in your participation in our research studies that evaluate stroke symptoms. May we have your permission to contact you now and in the future to describe our research studies and invite you to participate in a study? You are NOT obligated to participate if you join our REGISTRY, but if you agree to join this REGISTRY, you may be contacted by a center investigator or by his or her research staff.

○ Yes, I agree   ○ No, thanks

Today's Date ___ ___ ___
MM   DD   YYYY

First / Given Name _____

Last / Family Name _____

☐ Male   ☐ Female

Date of birth ___ ___ ___
MM   DD   YYYY

To enable us to contact you, please provide your current residential information

Number, Street / Route / P.O. Box _____

_____

City / Town _____

State / Province _____   Postal / Zip Code _____

Email _____

Primary Phone ___ ___ ___   Fax ___ ___ ___

Work Phone ___ ___ ___

Best person to contact by phone: *(circle)* SELF or OTHER:_____
name of other contact

How would you describe your ethnicity?

☐ Hispanic or Latino
☐ Not Hispanic or Latino

How would you describe your race? You may chose more than one answer if appropriate:

☐ American Indian/Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or other Pacific Islander
☐ White
☐ Other (specify)

Other _____

Which of the following symptoms did you have with your stroke? *check all that apply*

Date of stroke ___ ___ ___
MM   DD   YYYY

☐ Weak arm / hand on one side (*circle:* RIGHT or LEFT)

☐ Weak leg / foot on one side (*circle:* RIGHT or LEFT)

☐ Balance or coordination problems

☐ Difficulty walking

☐ Aphasia / Speech difficulty

☐ Difficulty Reading

☐ Difficulty Writing

☐ Attention / Concentration difficulty

☐ Personality / Level of motivation change

☐ Visuospatial / Drawing or recognition problems

☐ Memory Loss

☐ Other: _____

_____

Would you be willing to come to UNC (Chapel Hill, NC) for participation in a research study?

☐ Yes   ☐ No

If you do **NOT** have any stroke problems or symptoms, would you be willing to be contacted as a healthy subject?

☐ Yes   ☐ No

Thank you for completing this form. Please mail it to:

**Stroke Registry Coordinator
c/o Adam Jacks, PhD
Dept. of Allied Health Sciences
3105 Bondurant Hall
CB# 7190
Chapel Hill, NC, 27599-7190**

If you would prefer to register by phone or email, please contact the Stroke Registry Coordinator at:

919-966-9464
or
adam_jacks@med.unc.edu

To withdraw from this REGISTRY at any time, please email a request to adam_jacks@med.unc.edu or write:
Stroke Registry Coordinator, c/o Dr. Adam Jacks, Dept. of Allied Health Sciences,
3105 Bondurant Hall, CB#7190, Chapel Hill, NC 27599-7190

REGISTRY OF POTENTIAL STROKE RESEARCH STUDY PARTICIPANTS

General REGISTRY Information

The UNC Center for Stroke Related Research is engaged in a number of research projects for which we are always interested in recruiting study subjects. We have established a REGISTRY for Potential Study Participants as a way to have more interactive communication about on-going and new studies at the Center, and to encourage involvement in our research from people who are interested in research activities of the Center.

The front page of this paper is the REGISTRY form.
This form:

- Requests your consent to be contacted about our research studies.

- Requests information on how best to contact you about our research studies.

- Asks about your current stroke problems or symptoms.

- Asks if you would be willing to be contacted as a healthy volunteer, if you do not have any stroke problems or symptoms.

There is no compensation for joining our REGISTRY. However, some of the studies that REGISTRY enrollees are contacted about may compensate those who enroll in, and complete, the study.
The REGISTRY pertains to human subjects research and has been reviewed and approved by the UNC Institutional Review Board (IRB).

Your medical record will not be accessed as a part of this registry protocol. Permission from you to access your medical record for research may only be sought by researchers under each separate study in which you decide to participate.

Privacy Policy - Protection of Privacy

No person enrolled in the REGISTRY will be identified/ identifiable in any report or publication about the REGISTRY.

- Although every effort will be made to keep REGISTRY records private, there may be times when federal or state law requires the disclosure of selected records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-CH will take all steps allowable by law to protect the privacy of personal information.

Only individuals authorized to have access to REGISTRY information will have access. REGISTRY information is kept in a database protected by passwords and secured on a protected server.

Contact Information

If you have any questions about the REGISTRY or on-going research studies at the UNC Center for Stroke Related Research, please contact the Stroke Registry Coordinator at: jacksa@med.unc.edu or call 919-966-9464.

To withdraw from the REGISTRY at any time, email a request to jacksa@med.unc.edu or write:
Stroke Registry Coordinator, c/o Adam Jacks, PhD
Dept. of Allied Health Sciences, 3105 Bondurant Hall., CB# 7190 Chapel Hill, NC 27599-7190.

About the REGISTRY Form

Consent to be contacted: At the top of the REGISTRY form, we ask your permission to contact you now and in the future to describe specific research studies and invite you to participate in one or more studies.

- If you check the "Yes I agree" box and submit the form, you become part of our REGISTRY. (If you check "No thanks", you will not be included in our REGISTRY and you need not complete the remainder of the form or submit it.)

- If or when there is an appropriate study, REGISTRY volunteers will be contacted by a Center investigator or by his or her research coordinator to discuss the study. This contact should be relatively brief - to let you know a little about the study, to see if you meet basic eligibility criteria, and to see if you are interested in being considered for the study.

We cannot guarantee you will be contacted about or selected for a study, but we will do our best to identify appropriate studies. You are always welcome to contact us yourself when you identify a study that might be of interest to you.

- You would never be obligated to participate in a study.

- You may withdraw from the REGISTRY at any time by calling the Stroke Registry Coordinator at 919-966-9464 or emailing jacksa@med.unc.edu and stating that you wish to withdraw from the REGISTRY. Your withdrawal from the REGISTRY will be confirmed through a written or email response.

Information on how best to contact you: To be in effective communication with those who join the REGISTRY, we request current residential information, which is ideally the preferred way for you to be contacted. We will also be in contact with you via electronic mail.

- An important benefit of becoming part of the REGISTRY is the opportunity to speak directly with investigators or research coordinators, to see if a proposed study is particularly appropriate.

- Another benefit from joining the REGISTRY is our periodic communication with registrants about new and on-going studies in general and about the REGISTRY itself. This will occur at least once a year. The first communication will acknowledge your volunteering for the REGISTRY.

Your current stroke problems or symptoms: The REGISTRY form includes a few questions about any current problems or symptoms you might have in your extremities; in walking, balance, or coordination; in your speech, memory, visuospatial skills, attention, or concentration; and whether you have experienced a change in personality or motivation level. Your answers to these questions will allow us to do a better job of identifying appropriate studies for you.

Healthy volunteer: If you do not have any stroke symptoms or problems, we ask if you would be willing to be a healthy research subject.