DESCRIPTION:
You and/or your dependents (such as a child or elderly family member) are invited to join the Stanford Research Registry, which is a database of individuals interested in participating in Stanford research. Our goals are to improve human health and quality of life and to learn more about how to prevent and treat disease. The Stanford Research Registry team acts an intermediary between you and Stanford research teams. By completing and submitting the Stanford Research Registry form, you are giving the Registry team permission to include your personal and health information in our secure database. In turn, the Registry team may share your de-identified information with researchers within Stanford University. If we determine that you are eligible for a study, the Registry team will contact you on behalf of the Stanford researchers to ask if you are interested in participating. If you express interest, the Registry team will then share your identifiable information with the relevant research team. **You do not have to participate in any research study; and you do not have to answer any question on the form you don’t want to.**

TIME INVOLVEMENT: Filling out the form should take 10 – 15 minutes.

RISKS AND BENEFITS: There are no risks or benefits to filling out this form other than that you may be contacted to be in a research study. We cannot and do not guarantee or promise that you will receive any benefits from providing your contact information to the Stanford Research Registry.

PAYMENTS: There are no payments or costs associated with filling out this form.

PARTICIPANT’S RIGHTS: If you have read this form and have decided to participate in this project, please understand your participation is voluntary and you have the right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You have the right to refuse to answer particular questions. Your individual privacy will be maintained in all published and written data resulting from the study.

Authorization to Use Your Health Information for Research Purposes
In order to include your personal and health information in the Stanford Research Registry, and to use such information to determine if you are eligible for Stanford research studies, we need your prior authorization. By submitting your information to us in the Stanford Research Registry form, you are providing such authorization. Your information will only be used in accordance with this authorization, your informed consent, and as required or allowed by law. Please read this authorization form before providing your information.

When you submit the Stanford Research Registry form, you will be registered in our secure database – which will enable Stanford to determine if you are eligible for certain Stanford research studies now, or in the future, and to contact you to ask if you are interested in participating.

You do not have to provide this authorization. But if you do not, you will not be included in the Stanford Research Registry database. Agreeing to this authorization is not a condition for receiving any medical care.

If you do decide to participate, you are free to withdraw your authorization regarding the use and disclosure of your health information (and to discontinue any other participation in
the registry) at any time. After any revocation, your health information will no longer be
used or disclosed in the research registry, except to the extent that the law allows us to
continue using your information (for example, it may be necessary to use your information
in order to maintain the integrity of relevant research). If you wish to revoke your
authorization for research use or disclosure of your health information in this research
registry, you must write to: Karl Sylvester, MD, Research Registry, 800 Welch Road, Rm
245, Stanford, CA 94305 or call him at 650-497-3612.

Your health information related to this research registry that may be used or disclosed
includes your name, medical record number, any health information including lab results
or health history in your Stanford medical record (if applicable), diagnoses, gender, age
and any other information you have shared with us.

The following parties are authorized to use and/or disclose your health information in
connection with this research registry:

- The Protocol Directors, Karl Sylvester, MD and Kevin Schulman, MD
- The Stanford University Administrative Panel on Human Subjects in Medical
  Research and any other unit of Stanford University (Stanford IRB) as necessary
- Research Participation Program and Registry staff

Those parties listed may disclose your health information to the following persons and
organizations for their use in connection with this research registry:

- The Office for Human Research Protections in the U.S. Department of Health and
  Human Services
- Stanford University researchers who have a study you may qualify for and who have
  obtained permission from Stanford IRB to use the registry

Your information may be re-disclosed by the recipients described above, if they are not
required by law to protect the privacy of the information.

Your authorization for the use and/or disclosure of your health information will expire on
December 31, 2115. If you agree to participate in this research registry, please fill out the
attached Research Registry Form.

CONTACT INFORMATION: If you have any questions, concerns or complaints about Stanford
Research Registry, please ask the Protocol Director, Karl Sylvester, MD at joinresearch@stanford.edu
or 650-497-3612.

Independent Contact: If you are not satisfied with how this research registry is being conducted, or if
you have any concerns, complaints, or general questions about the research or your rights as a
participant, please contact the Stanford Institutional Review Board (IRB) to speak to someone
independent of the research team at (650)-723-5244 or toll free at 1-866-680-2906. You can also write
to the Stanford IRB, Stanford University, 1705 El Camino Real, Palo Alto, CA 94306.

If you agree to participate in this research registry, please fill out the Research Registry form.

This information sheet is for you to keep for your records.