

STANFORD UNIVERSITY Research Information Sheet		<i>IRB Use Only</i>
Protocol Director:	Karl Sylvester, MD	Approval Date: June 16, 2020 Expiration Date: June 30, 2020
Protocol Title: Stanford Medicine Research Registry		

DESCRIPTION: You and/or your dependents (such as a child or elderly family member) are invited to register in the Stanford Research Registry. Our goals are to improve human health and quality of life and to learn more about how to prevent and treat disease. We also want to learn how to best teach doctors and scientists. If you fill out the Stanford Research Registry form (either on paper or online), you are giving your permission for the research team to add your information to our secure database. If you are eligible for a study now, or in the future, the Registry team will contact you on behalf of Stanford researchers to see if you are interested in participating. **It does not mean you have to be a research participant and you do not have to answer any question on the form you don't want to.** Your information will only be shared with investigators within Stanford University. The Stanford Research Registry acts an intermediary between you and the researcher until you have indicated you would like to learn more about a study.

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

We will also need to obtain your authorization to use your private health information. Information about you and your health is personal and private. It generally cannot be used in a research study without your authorization. By you providing us your information will provide that 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 form before providing your information.

By filling out the Stanford Research Registry form, we would like to give you the opportunity to be registered in our secure database so that if you may be eligible for any of our studies now, or in the future, a member of the research team could contact you to see if you are interested in participating.

You do not have to agree to this authorization. But if you do not, you will not be able to participate in this research database. Agreeing to this is not a condition for receiving any medical care outside this registry.

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 study, 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 the research). If you wish to revoke your authorization for research use or disclosure

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of your health information in this study, 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 study that may be used or disclosed in connection with this research study 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 study:

- 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 study:

- The Stanford Biobank
- The Stanford WELL Registry
- The Office for Human Research Protections in the U.S. Department of Health and Human Services
- Other 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 Contact 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 attached Research Registry Contact Form.

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