Consent for Participate in Discovery
University of Missouri

Project Title: Participate In Discovery
Principal Investigator: Jerry Parker, PhD
IRB Number: 2008273

Purpose of Participate in Discovery
The purpose of Participate in Discovery is to create an opportunity for persons interested in participating in research to add their name to a list so that they can be contacted for specific research studies. If you add your name to the Participate in Discovery list, you may be contacted to ask if you want to participate in specific studies. You can either accept or decline any invitation.

Will You Use Any Of My Private Health Information?
No medical record information is used. You are asked to complete a few questions about your lifestyle. This will help researchers identify if you qualify for a study.

What If I Change My Mind?
Enrollment in Participate in Discovery will be completely voluntary. You will be able to opt-out at any time by contacting the Participate in Discovery team at https://medicine.missouri.edu/research/participate-in-discovery/ or by calling a private phone number 573-882-6273. Your information will be removed from the list. A decision to withdraw after registration will not affect you in any other way.

What Are the Benefits of Registering?
The benefits to enrolling in Participate in Discovery include the knowledge of contributing to the research mission of the University of Missouri. Additionally, enrolling in Participate in Discovery includes the possibility of direct or indirect benefits from human clinical trials or other research.

What Are the Risks of Registering?
Unauthorized access to personally identifiable information is a remote possibility. However, the risk is minimal because the registry data is stored in a secure web-based application, and all data transmission is encrypted.

What Are The Costs?
There are no costs to you for enrolling in Participate in Discovery.

Whom Do I Call If I have Questions or Problems?
If you have questions, concerns, or complaints about Participate in Discovery, you can contact the Participate in Discovery team at https://medicine.missouri.edu/research/participate-in-discovery/ or by calling a private phone number 573-882-6273.

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this
study, you may contact the University of Missouri Health Sciences Institutional Review Board
(which is a group of people who review the research studies to protect participants’ rights) at
(573) 882-3181.

What about Confidentiality?
To minimize unauthorized access, Participate in Discovery list will be accessed only by the list manager.

**HIPAA AUTHORIZATION**

Authorization for the Use and Disclosure of Personal Health Information
Resulting from Participation in a Research Study

**Purpose:**
State and federal privacy laws protect the use and release of your health information. If you decide to give your permission to participate in the study listed above, you must read the Consent Form. This form describes the different ways that the researcher, the study team and the sponsor may use your health information for the research study.

1. **Description of your Protected Health Information that is to be used:**
My authorization applies to the information described below. **By law,** the information must be limited to the minimum necessary information needed to accomplish the purpose of the research.

- [x] Name
- [ ] Contact information such as address, phone number
- [ ] Radiology Images
- [ ] Radiology Imaging Reports
- [ ] EKG
- [ ] Progress notes
- [ ] History and Physical exams
- [ ] Operative Reports
- [ ] Pathology Reports
- [ ] Laboratory Reports
- [ ] Photographs and or Videotapes
- [ ] Other (please list) -

- [ ] Discharge Summaries
- [ ] Health Care Billing or Financial Records
- [ ] Consultations
- [ ] Medications
- [ ] Emergency Medicine reports
- [ ] Dental Records
- [x] Demographic information such as age, race etc.
- [x] Questionnaires, Surveys and/or Subject Diaries
- [ ] Audiotapes

2. **Who may receive your information?**
The primary investigator listed at the top and the study team may use and/or disclose your information to the following person(s) or class of persons:

Compliance and Safety Monitors, the MU Health Sciences Institutional Review Board, Government agencies, the sponsor (insert name below)
4. **Purpose of the use or disclosure**
My PHI will be used and/or disclosed upon request for the following purposes:
Publications and presentation that will not identify me, auditing, administrative and billing reviews, study outcomes including safety and efficacy

*If applicable add the following information as well:

- [ ] My treatment during the study
- [ ] Submission to the government agencies that may monitor the study
- [ ] Describe any other disclosure

5. **Expiration date or event**
Unless you revoke (take back) your authorization, your authorization will allow us to use and/or disclose your information will
- [ ] Expire at the end of research study
- [x] There will be no expiration date (for example when creating a database)

6. **Your right to revoke or withdraw authorization**
I understand that I have a right to revoke this authorization at any time. My revocation must be in writing in a letter sent to the Participate in Discovery team at MA204 Medical Sciences Building, MU School of Medicine, One Hospital Drive, MA204, Columbia, MO 65212 or by calling a private phone number 573-882-6273. I am aware that my revocation is not effective to the extent that the persons I have authorized to use and/or disclose my PHI have already acted in reliance upon this authorization.

7. **Statement that re-disclosures are no longer protected by the HIPAA Privacy Rule**
I understand that my personal health information will only be used as described in this authorization in relation to the research study. I am also aware that if I choose to share the information defined in this authorization to anyone not directly related to this research project, the law would no longer protect this information. In addition, I understand that if my personal health information is disclosed to someone who is not required to comply with privacy protections under the law, then such information may be re-disclosed and would no longer be protected.

9. **Suspension of right to access personal health information**
I agree that I will not have a right to access my personal health information obtained or created in the course of the research project until the end of the study.

10. If I have not already received a copy of the University of Missouri Healthcare Privacy Notice, I may request one. If I have any questions or concerns about my privacy rights I should contact, the HS Privacy Officer at 573-882-9054 or the Campus Privacy Officer at 573-882-9500.