**RESEARCH CONSENT FORM**

**Study Title**

**PI Name**

**PI Contact Information**

We are asking you to take part in a research study at the University of Kansas Medical Center (KUMC) being done by [PI name]. The study is for patients who [describe the qualifying condition.] Being in this study is optional. You can get services at KUMC without being in the study.

People who join the study will allow information about their medical care to be saved in a computer database. The information will include [your medical history, treatments, lab results, scans, surveys about your family’s health, questionnaires about your symptoms, etc.] Researchers can use this information to answer questions about [topics of the various analyses].

Being in the study will not add any time to your normal clinic visits. The information is already being collected as part of your treatment. [Alternatively, describe additional time for questionnaires that will be collected at the time of the regular clinic visit.] Your information will be updated [discuss frequency] as long as you are a patient at KUMC.

[Insert if applicable] Your participation in this study and your study information may be put into the University of Kansas Health System electronic medical record and combined with your health information from your clinical care. The health system may use and share this information for other purposes described in the Notice of Privacy Practices.

The only risk to you is a possible loss of confidentiality. We will follow the HIPAA laws about privacy. Your study information will be kept on a secure computer. We will keep it indefinitely. The study information will be kept separately from your name and other personal identifiers. Study information will be shared with members of the research team. It might also be seen by people who monitor research if there was an audit.

[If applicable] We will share your study information with others outside KUMC who are also doing research on [condition]. It will be labeled in a way that cannot identify you. It is possible that information shared outside KUMC might be released by others. If this happens, your information will not be protected by the HIPAA laws. Removing personal identifiers will lower the risk that the information could be traced back to you.

If you want to cancel your permission to use your health information, please write to [PI Name]. The mailing address is [PI Name], University of Kansas Medical Center, 3901 Rainbow Boulevard, Kansas City, KS 66160. If you cancel permission to use your health information, we will not gather any new information about you; however, we may use and share information that was gathered before we received your cancellation. You can ask for personal identifiers to be removed from the information we keep.

If you have questions about this study, please contact [insert researcher’s contact information]. For questions about your rights as a research participant, you may contact the KUMC Institutional Review Board (IRB) at (913) 588-1240 or [IRBhelp@kumc.edu](mailto:IRBhelp@kumc.edu). You will be given a signed copy of this consent form to keep for your records.

If you agree to be in the study please sign and date below:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Print Participant’s Name

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Participant Date

[If applicable]

In the future, we may conduct additional studies about [condition under study]. If you agree, the we will contact you to see if you want to join future studies. You would receive a separate consent form describing the future studies.

* Yes, I would like to be contacted if I qualify for future studies. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature

* No. Please do not contact me about future studies. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature