**Consent to Participate in a Research Study**

Subject’s Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ IRB Study #: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Medical Record/Subject ID #: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

You or your child is being asked to participate in a research study. A research study is how scientists (doctors, nurses and other professionals) try to understand how things work and gain new knowledge. A research study can be about how the body works, what causes disease, how to treat diseases, or what people think and feel about certain things.

Before you decide whether you or your child will participate in this research study, the investigator must tell you (i) the key information that will help you understand the reasons why to participate or not participate in the research (ii) purposes of the research study, the activities that will take place - these are called procedures, and how long the research will last; (iii) any procedures that are experimental (being tested); (iv) any likely risks, discomforts, and benefits of the research; (v) any other potentially helpful procedures or treatment; and (vi) how your privacy will be maintained; (vii) if identifiable private information or identifiable specimens will be kept for future research or shared with other researchers without consent for that other research.

Where applicable, the investigator must also tell you about (i) any available payment or medical treatment if injury or harm occurs; (ii) the possibility of unknown risks; (iii) situations when the investigator may stop your participation; (iv) any added costs to you; (v) what happens if you decide to stop participating; (vi) when you will be told about new findings that may affect your willingness to participate; and (vii) how many people will be in the study; (viii) the fact that your biospecimens may be used for commercial profit and whether you will share in that commercial profit; (ix) if the research includes whole genome sequencing.

If you agree to participate, you must be given a signed copy of this document and a copy of the approved consent form for this study written in English.

You may contact \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ at \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ any time you have questions about the research or about what to do if you are injured. If you have any questions about your rights as a research subject you may contact the Institutional Review Board, at (508) 856-4261, by email at irb@umassmed.edu, or by mail at the following address: UMMS Institutional Review Board (IRB)

362 Plantation Street, Ambulatory Care Center, 7th Floor

Worcester, MA 01605

Your participation in this research is voluntary (your own choice), and you will not be penalized or lose benefits if you refuse to participate or decide to stop.

Signing this document means that the research study, including the above information, has been described to you orally, and that you voluntarily agree to participate.

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Signature of Participant Date

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Signature of Legally Authorized Representative Date

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Printed Name/Signature of the Witness Date