**APPENDIX D: GENETIC/BIOBANK RESEARCH**

Date form completed:

 **Study Title:**

1. Will new biological material be obtained for genetic research? [ ]  Yes [ ]  No
2. If yes, will genetic research be conducted on pre-existing biological material?

[ ]  Yes [ ]  No

1. Please describe how biological material will be used, including what genetic testing will be done on the material:
2. Will consent be obtained for genetic research? *(Separate consent form for genetic testing should be considered, if genetic research is an optional component of participation)*

[ ]  Yes [ ]  No

1. If no, please also complete **Appendix E**: Waiver of Consent Considerations or **Appendix B:** Retrospective Biological Sample Analysis if the samples are being collected retrospectively.

1. If yes, during the consent process, will participants be informed of the potential risks or benefits associated with the findings that may be revealed by participating in this study (*in particular, genetic research*)? [ ]  Yes [ ]  No
2. If no, please justify:
3. If yes, have participants/impacted individuals been provided with the opportunity to make an informed choice about whether to receive information about findings that may be revealed by participating in this study? [ ]  Yes [ ]  No
4. If no, please justify:
5. During the consent process, will the possibility of incidental findings revealed by participating in this study be discussed with the participant? [ ]  Yes [ ]  No
6. If yes, will participants be given the opportunity to express their preferences about whether the information will be shared with their biological relatives or others whom they have a relationship (family, community, groups)? [ ]  Yes [ ]  No
7. If yes, how will this information be communicated?
8. Will genetic counseling be made available to participants/impacted individuals if needed? [ ]  Yes [ ]  No
9. Please describe the process that will be followed to facilitate access to genetic counseling:
10. Describe when and how samples will be discarded or destroyed:
11. Please indicate the location where samples will be collected for research purposes (i.e. location in the hospital or community):

1. Will any of the samples that are collected be retained for future use?

[ ]  Yes [ ]  No

1. If yes,
2. describe where the samples will be kept, the length of time they will be stored, and the process of disposal:
3. Include a separate signature line requesting consent to retain the samples in the consent form.
4. Describe whether there is any anticipated linkage of the sample to information about the patient and what measures will be taken to protect the privacy of the participants: