**Department Name**

**Protocol Title:**

**Principal Investigator/Key Research Personnel:** (including all names, titles, description of the roles in the research, and contact information-For student projects, the faculty mentor must be included)

**Introduction:**

**The purpose of this form is to provide you with information about participation in a research study and offer you the opportunity to decide whether you wish to participate. You can take as much time as you wish to decide and can ask any questions you may have now, during or after the research is complete. Your participation is voluntary.**

**What is the purpose for the research study?**

* **Using lay terminology at a reading level appropriate to the targeted population, describe the purpose for the study.**

**What will I be asked to do?**

* **Describe all research activities, including their purpose and duration. The participant should have a clear understanding of what they will be asked to do and the time commitment for participation from your description.**
* **Describe what types of measures you will use and explain who will administer them. Provide examples of the types of questions you are planning to ask when appropriate.**

**What are the possible risks of participation in this research study?**

* **Describe any reasonably foreseeable risks and/or discomforts associated with participation in the research consistent and how these risks will be mitigated and/or managed. The description must be consistent with the information regarding risks included in the protocol application.**
* **If support services will be available/provided, this should be described and a separate list provided to the participant.**

**What are the possible benefits of participation in this research study?**

* **Describe any reasonable benefits expected from participation in the research. The description should distinguish between direct and indirect benefits and be consistent with the information regarding benefits in the protocol application. (e.g.-There may not be any direct benefits to the participant; however, there may be benefits to others, organizations, institutions, etc.).**
* **Describe any key information related to alternatives to participation in the study (when appropriate).**

**How will my privacy be protected?**

* **Describe the provisions in place to protect the privacy interests of the participant. This may include but is not limited to the location where the research will occur.**
* **Describe in what form and with whom the results of the research will be shared. This may include but is not limited to a description of data coding, publication, web/conference/workshop presentation, etc.**
* **The information included in this section should be consistent with the information regarding participant privacy included in the protocol application**

**How will my data be maintained to ensure confidentiality?**

* **Describe whether participants’ information or biospecimens will or will not be stripped of identifers and used for future research.**
* **Describe the methods you will use to maintain the confidentiality of the data. Include in your description how the data will be maintained (e.g.-paper, electronic, desk or lap top computer or other electronic device, etc.), the method for confidentiality and data security (e.g.-password protected computer, encrypted files, locked cabinet/office, etc.), and name the persons that will have access to the data.**
* **If data will be shared, describe how data will be transferred or transmitted. If data will be transmitted via electronic networks, describe how you secure data during transit. The persons with whom you will share the data should be named.**
* **If data will be coded, describe the method (e.g.-assignment of ID #’s/pseudonyms) and name who will have access to the key to the code.**
* **The information included in this section should be consistent with the information regarding confidentiality included in the protocol application.**
* **Must include *one* of the following statements about identifiable private information/identifiable biospecimens:**

**A statement that identifiers might be removed from the identifiable private information/identifiable biospecimens and that, after such removal, the information/biospecimens could be used for future research studies or distributed to another investigator for future research studies without additional consent from the participant or the legally authorized representative is not included. *OR***

**A statement that the participant’s information/biospecimens collected as part of the research, even if identifiers are removed, will not be used or distributed for future research studies is not included.**

**ONLY when appropriate include the following headers:**

**Will photographs, audio, video, or film recording be used?**

* **If participants will be recorded/photographed in any manner, you must include a description of the purpose for them, how they will be used, who will have access to them and the disposition of them once the research study is complete.**
* **Checkboxes must be included at the end of the consent form for participants to indicate agreement for the recording. A separate checkbox for each type of recording should be created.**
* **The information included in this section should be consistent with the information regarding confidentiality included in the protocol application.**

**Will I receive compensation for participation?**

* **Describe the method of compensation (e.g.-cash, gift card, course credit, etc.), and how it will be awarded (e.g.-per task, per session, etc.).**
* **If you will hold a raffle/drawing, the odds of winning must be described.**
* **With the understanding that compensation cannot be contingent upon full participation, describe how compensation will be awarded if a participant withdraws prior to completion. Compensation should be pro-rated in a manner that recognizes the time and effort of the participant prior to withdrawal.**

**Will clinically relevant research results will be returned to the participants?**

**Will research activities include whole genome sequencing?**

**Information about possible commercial profit.**

**Information regarding Certificates of Confidentiality.**

**Information regarding situations of abuse/risk/harm if/when mandated reporting is indicated.**

**Information regarding legal subpoena.**

**What are my rights as a research participant?**

* **Your participation is voluntary.**
* **You may skip and/or refuse to answer any question for any reason.**
* **You are free to withdraw from this research study at any time without penalty.**

**Whom may I contact with questions?**

* **For questions, concerns or more information regarding this research you may contact *include the names and contact information of the Principal Investigator and key research personnel.***
* **If you have questions or concerns about your rights as a research participant you may contact the Syracuse University Institutional Review Board at (315) 443-3013.**

**All of my questions have been answered, I am 18 years of age or older, and by signing this consent form, I agree to participate in this research study. I have received a copy of this form for my personal records.**

**­­­­­­­­­­­­­­­­­------------------------------------------------------------ Date: ­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Printed Name of the Participant**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Signature of the Participant**

**------------------------------------------------------------ Date: ­­­­­­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Printed Name of the Researcher**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Signature of the Researcher**