**Genetic Research Consent Language**

**INSTRUCTION:** If the research plans to conduct genetic research, add the following language to Consent Section ‘**What are the risks of harm to you?**’ See below a definition of what qualifies as genetic information. Delete all text in blue before uploading the language to the consent document.

Psychological or Social Risks Associated with Loss of Privacy:

Although your genetic information is unique to you, you do share some genetic information with your children, parents, brothers, sisters, and other blood relatives. Consequently, it may be possible that genetic information from them could be used to identify you. Similarly, it may be possible that genetic information from you could be used to help identify them. Further, patterns of genetic variation also can be used by agencies to identify a person or their blood relatives (for example, to establish relationships between parents and their children).

Economic Risks of Harm:

Since some genetic variations can help to predict the future health problems of you and your relatives, this information might be of interest to health providers, life insurance companies, and others. Therefore, your genetic information potentially could be used in ways that could cause you or your family economic distress.

There is a federal law call the Genetic Information Nondiscrimination Act (GINA) that helps protect against genetic discrimination. In general, this law makes it illegal for health insurance companies, group health plans, and most employers to discriminate against you based on your genetic information. This law generally will protect you in the following ways: (1) health insurance companies and group health plans may not request your genetic information that we get from this research; (2) health insurance companies and group health plans may not use your genetic information when making decisions regarding your eligibility or premiums; and (3) employers with 15 or more employees may not use your genetic information that we get from this research when making a decision to hire, promote, or fire you or when setting the terms of your employment. However, it does not protect you against discrimination by companies that sell life insurance, disability insurance, or long-term care insurance.

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\*GINA, the federal law, defines genetic information as information about:

* An individual’s genetic tests (including genetic tests done as part of a research study);
* Genetic tests of the individual’s family members (defined as dependent and up to and including 4th degree relatives);
* Genetic tests of any fetus of an individual or pregnant family member, and genetic tests of any embryo legally held by an individual or family member utilizing assisted reproductive technology;
* The manifestation of a disease or disorder in family members (family history); or
* Any request for, or receipt of, genetic services or participation in clinical research that includes genetic services (genetic testing, counseling, or education) by an individual or family member.

Genetic information does not include information about the sex or age of any individual.

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