

**Consent Form Addendum
Storage, Future Use and Future Contact**

Storage and Future Use of Biological Samples, DNA and/or Data

[Include the following paragraphs if there will be retention of samples, DNA and/or data at CUMC in identifiable form and possible use of the same in deidentified form. You must ensure that Section 7 of the consent form is consistent with retention by confirming that the option “or retain the sample indefinitely” has been selected. If it has not, this Section is not applicable and should be omitted.]

After this study, where will my samples, DNA and/or data be stored and who will have access to them?

We would like to store the biological samples that you agreed to provide as part of this study, the DNA taken from these samples and/or the data obtained from the study and possibly use them for future research. They will be stored at CUMC either with the researchers on this study or in a central storage facility called a **repository**.

With your permission, your samples, DNA and/or data will be **stored** at CUMC indefinitely in **identifiable** form. This means that your samples, DNA and/or data will be labeled with a code number that the researchers on this study or the people managing the repository may be able to link to you.

Also with your permission, your samples, DNA and/or data may be **used** by other Columbia researchers or researchers at other institutions, including commercial companies, for research on your *[select: medical condition(s), symptom(s)]* or other conditions. If they are given to researchers who are not researchers on this study, they will only be given in **deidentified** form. This means that your name and other identifying information have been permanently removed from your samples, DNA and/or data **OR** that your samples, DNA and/or data are coded and the researchers who use them do not have the key to the code. *[Note that the procedures in any repository protocol that will store this material for future use must have storage provisions that are consistent with these statements.]*

Any future testing or research using your samples, DNA and/or data may lead to the development and use of information, products, tests and treatments having commercial value. You will not receive any compensation that may result from these tests or treatments.

☐ **I agree** ☐ **do not agree** to the **storage** of my samples, DNA and/or data at CUMC in identifiable form after completion of this study.

☐ **I agree** ☐ **do not agree** to the **use** of my samples, DNA and/or data for future research and/or testing, including for commercial purposes, that may or may not be related to this study. I understand that my samples, DNA and/or data will only be given to researchers in deidentifiable form.

You can change your mind regarding storage and future use of your samples, DNA and/or data at any time. Please see Section 16 of the consent form for further information.

Future Contact

[Include the following paragraphs if permission for future contact will be requested.]

Why might the researchers want to contact me in the future?

We may want to contact you for additional information or to get a new sample of your *[select: blood, tissue]* in order to learn more about the research findings from this study. We may contact you directly or through your doctor. We may ask you provide a new sample or additional medical information, participate in other research studies or allow us to use your samples, DNA and/or data in identifiable form. If a biological sample, your participation in future research or our use of your samples in identifiable form is requested, you will be asked to sign an additional form to agree to this.

In addition, in the future, we may want to contact you if we learn more about the genetic basis for your *[select: medical condition(s), symptom(s)]* or other medical conditions or if we are more certain about identifying the genetic cause of your *[select: medical conditions(s), symptom(s)]* that might give you the opportunity to obtain treatment or better treatment for your *[select: medical condition(s), symptom(s)]*.

☐ I agree ☐ I do not agree to being contacted in the future for research to provide an additional biological sample or medical information, to receive information about other research studies, or with a request to use samples, DNA and/or data with my identifying information attached.

☐ I agree ☐ I do not agree to being contacted in the future to receive additional information for the treatment of my *[select: medical condition(s), symptom(s)]*.

You can change your mind regarding being contacted in the future at any time. Please see Section 16 of the consent form for further information.

Statement of Consent

[When finalizing this document, please make sure the statement of consent and signatures are on the same page. If there are any large areas of blank space as a result, add the statement, "This section intentionally left blank."]

Statement of consent

I have read this addendum and the options for future storage and use of my Biological Samples, DNA and/or Data, and possible future contact, have been explained to me. My decisions about the options have been initialed above.

A copy of this addendum will be provided to me after I sign it.

By signing this addendum, I have not given up any of my legal rights.

Signatures

Omit signature lines that do not apply. If the signature line remains, the expectation is that it will be used at the time of each enrollment.

Research Participant

Date

Print Name of Research Participant

[If this consent also serves as the permission from a surrogate, please include a “legally authorized representative” signature line.]

Legally Authorized Representative, Parent or Legal Guardian

Date

Print name of Legally Authorized Representative, Parent or Legal Guardian

Person Obtaining Consent

Date

Print Name of Person Obtaining Consent

Witness

Date

Print name of Witness

The signature of a witness is only required for minimal risk studies when obtaining consent from:

- a Non-English Speaking Research participant using the short form process, or
- a person who is physically not able to read, talk or write.