

NIGMS Human Genetic Cell Repository MODEL INFORMED CONSENT FORM

I consent to the collection of ___ ml(___ tsp) blood/skin biopsy from myself/my child for submission to the Coriell Cell Repository, a research resource supported by the National Institutes of Health. The Repository collects, stores, and distributes cell cultures and DNA samples from people with many kinds of disorders, from unaffected family members, and from other healthy people. My sample will be used to create a cell line that will be added to the Repository's collection. The purpose of this collection is solely to make specimens available for use in research and teaching and as standards in clinical genetics laboratories. Submission of my sample to the Repository may give scientists valuable research material that can help them to develop new diagnostic tests, new treatments, and new ways to prevent diseases. Scientists will not use my sample, or material isolated from it, for commercial products or services.

The Repository will take measures to protect my privacy. My blood or tissue specimen will be given a code number, my name will be removed, and the Coriell Cell Repository will not give out my name to the scientists who receive the samples. Some information, such as age, sex, diagnosis, and race, will be made available to the Repository and scientists. There can be no absolute guarantee of confidentiality, however, and there is a small chance that some research may yield results that will have a negative impact on me, my family, other individuals, or groups. This impact may include insurability, employability, and/or family relationships.

The Repository has obtained a Confidentiality Certificate from the Federal Government to help insure my privacy. This Certificate means that the Repository cannot be forced to tell people who are not connected with the study about my participation without my written consent.

There will be no direct benefit or payment to me for participating, but my sample may benefit the community at large or some particular group. Because researchers will not have access to my identity, it will not be possible to provide me or my physician with the results of studies that might be performed using my specimen.

The medical risks of providing these specimens are small. The risk of drawing blood is minor transient pain and slight possibility of bruising. The risk for skin biopsy is mild local pain, slight bleeding, the chance of a small scar, and slight chance of infection.

It is possible that data resulting from use of my sample may eventually be used in a research publication. In that event, no individual's identifying information will be included, as this information will not be available to the researchers.

My donation is voluntary, and if I choose not to participate there will be no penalty or loss of benefits to which I am entitled. My sample will stay in the Repository indefinitely and I will not be able to withdraw it.

(Signature) _____
(Relationship) _____
(Date) _____
(Submitter) _____
(Submitter address) _____

If I have any questions or complications relating to collection of this specimen, I should contact (name) _____ (phone) _____, who collected the specimen. If I have any questions about the Repository, I should contact the Principal Investigator for the NIGMS Human Genetic Cell Repository, Coriell Institute for Medical Research, 403 Haddon Avenue, Camden, New Jersey 08103. (Telephone: 800-752-3805). If I have questions about my rights as a research subject I should call _____ (representative of submitter's IRB)

To contact the CORIELL CELL REPOSITORIES:

Write: 403 Haddon Avenue; Camden, New Jersey 08103; USA

Call: 800-752-3805 in the United States; 856-757-4848 from other countries

Fax: 856-757-9737

e-mail: ccr@coriell.org