

NIGMS HUMAN GENETIC CELL REPOSITORY

ASSENT FORM

What is Assent?

Assent is the process of obtaining authorization to collect a specimen from individuals who are not able to give consent for themselves. Legally authorized representatives must provide consent for children and cognitively impaired subjects to donate a sample, but the investigator/submitter must attempt to obtain assent from the subject if it is possible. Children aged 7 through 17 can give authorizations by signing this assent document. This form is to be used in addition to the NIGMS Human Genetic Cell Repository Informed Consent Form (Form 1401-63).

What is the NIGMS Human Genetic Cell Repository?

The NIGMS Repository is a biobank. A biobank is a collection of samples from people's bodies that are stored in a safe place. Cells from people with inherited diseases are stored in the NIGMS Repository. We are trying to help researchers find out about the causes of diseases that run in families. Scientists want to find the causes of disease so they can help doctors to cure the disease or even stop it from happening in the first place.

What will happen if I participate?

If you want to donate a sample, this is what will happen. We will take a small amount of blood from your arm or a small piece of skin from the inside of your arm. This sample will be used to make more samples that can be given to the scientists to study.

There are some parts of the study that might hurt or upset you when the blood or skin is taken, but we will make it as comfortable as possible for you. You might feel a pinching or burning for a few minutes or there may be a little bleeding that needs a BandAid.

Do I have to participate?

You can decide yourself if you want to donate a sample. We do not know if donating a sample will help you, but someday we may learn something that will help other people. You do not have to donate a sample. It is up to you. You will still be taken care of even if you decide that you do not want to be in the study.

If you want to donate a sample, please sign or print your name.

I,

(Print your name on the line above)

want to donate a sample to the NIGMS Repository.

Signed: _____

Date: ___

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