

Frequently Asked Questions

I'd like to donate cells. How do I do that?

First, contact the NIGMS Repository at NIGMS@coriell.org to let them know you are interested in donating blood, skin biopsy tissue, or both. They will walk you through the process and send you a sample collection kit. The kit has everything you need to safely store and send your sample back to the biobank, including the blood or skin tissue tubes, a pre-paid shipping label, and all the required paperwork. They also accept donations from family members of an individual affected by Cerebral Creatine Deficiency Syndromes, as long as the affected person is also submitting a sample.

Second, you'll need to have your sample collected. The NIGMS Repository accepts either blood draws or skin tissue punches which can be taken at your next doctor's appointment. It can be helpful to discuss the donation process with your doctor beforehand to ensure the sample collection is streamlined. Once the sample has been taken, follow the instructions to package it up and send it back. It is also encouraged to send as much clinical information as you are willing to share. The most common documents received are physician summary letters and genetic testing results. The more details attached to each sample, the more helpful the cells are to future researchers.

My child has already had a skin biopsy, can that be used?

Your doctor may be able to donate the sample to the NIGMS Repository. Please get in touch with your doctor and the ACD to help facilitate this process.

If your child's skin biopsy was converted into a type of cell line called a fibroblast, then it can be easily shared with the NIGMS repository team. The biobank will cover the cost of shipping the fibroblast cell line from the doctor or researcher's laboratory back to Coriell.

When I make a donation to Coriell, is that approved by an ethical or institutional review board?

Yes, since the NIGMS Repository at Coriell is funded by the NIH, they must obey a certain ethical standard that is led by Coriell's Institutional Review Board. In addition, any researcher that is interested in using Coriell's cell lines must sign a Material Transfer Agreement to ensure that the researchers are qualified.

Is my personal information protected?

All samples are de-identified immediately once they enter Coriell, and all personal identifying information is removed from your sample. Privacy is of the utmost importance in human subjects research and thus, Coriell takes many precautions to ensure that your identity is safe and secure. They have also obtained a Certificate of Confidentiality from the National Institutes of Health to ensure the privacy of all donors.

The NIGMS Repository will not give out your name or any other identifying information to the scientists who receive the samples. Some personal health information, such as age at the time of collection, gender, diagnosis, race, and ethnicity or country of origin will be made available to scientists to assist with their studies.

Do you need a skin biopsy or just a blood donation?

The NIGMS Repository does accept both skin biopsies and whole blood, though donating both is *not* required.

Who can collect a skin biopsy?

Though most doctors are capable of performing a skin biopsy, dermatologists generally have the most experience performing skin biopsies. The repository regularly sees something called a skin punch biopsy, which uses a small tool to take 2-4 mm² of tissue from the forearm. It may be helpful to speak with your doctor beforehand to ensure that the biopsy runs smoothly.

Who has access to the samples in the NIGMS Coriell biobank?

Every qualified investigator in the world has access to these samples. Our customer service team and scientific liaisons verify that the customer is qualified before they even make a purchase (each person must create an online account with us before they can start purchasing samples). The customer also signs an MTA, which their "institutional signing official" must also sign. The signing official must have legal signing abilities and differs with each academic and commercial institution.

Overall, the NIGMS's philosophy is that the more researchers that have access to rare disease samples, the more likely a break through is to occur. We also track publications that utilize our samples and then link them to the sample page so that future customers can read these papers for reference. This is a good way to look into what type of research is occurring with each sample or even a collection of samples.

What if I do not want to continue keeping samples with the Coriell biobank?

Donors can have their samples withdrawn from the repository at any time. Contact the NIGMS Repository at NIGMS@coriell.org for more information.