



Standard Operating Procedure for Destruction/Removal of Samples from the NINDS Repository

A submitter who wishes to have a sample permanently removed from the NINDS Repository must have language in their IRB consent form under which the sample was collected that indicates that sample removal is permitted.

A submitter who is informed by a subject that he wishes to have a sample removed, must inform both the PI of the Repository, Dr. Roderick Corriveau, and the Project Officer, Dr. Katrina Gwinn, in writing, of this request.

The submitter must supply the NINDS ID or the local Subject ID for the sample. This must be included in the request or the sample will not be able to be located due to the masking system that de-identifies samples. In addition to the submitter's request, a request letter signed by the subject, with all identifying information removed, must also be supplied to Coriell and the Project Officer. The submitter's request must refer to that letter. Additionally, the submitter must supply a letter from the IRB indicating that this request is valid under their institution's IRB.

Coriell will confirm that this ID number corresponds with a sample submitted by that submitter.

With the Project Officer's concurrence, Coriell will make a reasonable effort to locate and destroy the sample. Coriell is not able to contact any investigators to whom the sample has been distributed, and therefore, these already distributed samples will not be retrieved. Note, however, that a recipient of a withdrawn sample has no identifying data on the subject.

In cases where the submitter has not retained the NINDS ID number or the local Subject ID number, Coriell's de-identification process does not allow tracing of the sample, and thus a destruction request cannot be completed. However, Coriell will make all reasonable efforts towards this goal.

Within 60 days of the request, Coriell will inform the Investigator of the outcome of this effort. This outcome will be one of the following: sample destroyed; sample not identifiable based on information given; destruction not possible due to lack of appropriate documents per above requirements.