

The “*NINDS Repository Sample Recipient/Submitter Code of Conduct Agreement*” binds NINDS Repository Sample Recipients and Submitters to a set of requirements that respect issues of participant confidentiality and research intent agreed to by sample donors. Given agreement to these conditions, the NINDS Repository supplies only contact information to/from scientists who donated samples to (Submitters) or requested samples from (Recipients) the Repository. Failure to abide by any element within this *Code of Conduct* may result in the revocation of approved access to any or all samples and datasets through the NINDS Repository at Coriell.

The following is the *Code of Conduct* that NINDS Repository Sample Recipients agree to abide by to be placed in touch with NINDS Repository Submitters, and vice versa:

1. Sample Recipients will make no attempt to identify or contact individual whose samples and data of any kind are present in the NINDS Repository.
2. Sample Recipients and Repository Submitters will not distribute any data to any entity or individual beyond those specified in their collaboration request.
3. Repository Sample Recipients and Sample Submitters will report any miss-use of information received from a NINDS Repository submitter as soon as possible by contacting the NINDS Repository team at NINDS@coriell.org
4. Repository Submitters who enter into a collaboration agreement are responsible for ensuring that all conditions specified in the original IRB-approved informed Consent are adhered to in the collaboration. The collaboration cannot utilize any de-identified clinical data, and cannot use any clinical data that is not permitted in the original IRB-approved Informed Consent document.
5. Following NINDS Repository staff review of the original IRB-approved Informed Consent, NINDS and/or the NINDS Repository have the right to add specific limitations/prohibitions to the proposed collaboration.
6. The addendum set boundaries within which the collaboration can function; the addendum per se does not mandate the collaboration.

NINDS Repository Sample Recipient/Submitter Code of Conduct Agreement**Addendum for IRB-Approved Consent submitted by NINDS Repository Sample
Submitter**

(Prepared by the NINDS Repository)

Requested activities permitted by the Consent:

Requested activities prohibited by the Consent:

NINDS Repository Sample Recipient/Submitter Code of Conduct Agreement

Please acknowledge only one of the following which applies to you:

I requested samples from the NINDS Repository and I wish to make the connection with the sample submitter(s) who submitted samples I obtained.

Or

I submitted samples to the NINDS Repository and I agree to be contacted by a sample recipient(s) who received samples submitted by me.

By signing below, I understand and agree to adhere to the terms and conditions stated in this *Code of Conduct* and *Addendum* (if applicable).

Name of Institution: _____

Name of Principal Investigator: _____

Signature of Principal Investigator: _____

Date: _____

Submit to:
NINDS Repository at Coriell Institute for Medical Research
NINDS@coriell.org
FAX: 856-966-5067