

NINDS Repository Investigator Tracking Data Form

Approval to submit must be renewed at least annually, generally at the time of IRB re-approval

Investigator Contact Information:

Name:

Address:

E-mail:

Phone:

Fax:

Study Coordinator:

Name:

Address:

E-mail:

Phone:

Fax:

Funding Information:

Funded By: NINDS Other (specify): _____

Grant Number: _____ Start Date: _____ End Date: _____

Grant Title: _____

Grant Principal Investigator: _____

Sample Collection Disorder Category Information:

Please select one disorder category (subcollection), plus controls if applicable, per application.

If more than one disorder category is to be banked please submit a separate application (this form) for each.

Please list all relevant diagnoses:

- | | |
|-------------------------------------------------------------------|-------|
| <input type="checkbox"/> Parkinsonism | _____ |
| <input type="checkbox"/> Epilepsy | _____ |
| <input type="checkbox"/> Cerebrovascular Disease | _____ |
| <input type="checkbox"/> Motor Neuron Disease | _____ |
| <input type="checkbox"/> Tourette Syndrome | _____ |
| <input type="checkbox"/> Dystonia | _____ |
| <input type="checkbox"/> Huntington's Disease | N/A |
| <input type="checkbox"/> Population/Spousal/Family-Based Controls | N/A |

Ethnic and Racial Characteristics:

a) Hispanic _____%; Non-Hispanic _____%

b) Caucasian _____%; African American/Black _____%; Asian _____%;

Pacific Islander _____%; American Indian _____%; Mixed Race _____%; Other _____%

Submission Category: please check ONE (subject to approval by NINDS):

- Blood for DNA preparation and for possible cell culture
 Skin biopsy for fibroblast culture and for DNA preparation

Embargo Period:

Blood for DNA Preparation Options:

- Release immediately Release 1 year after submission Release 2 years after submission

Skin Biopsy for Fibroblasts Options:

- Release immediately Release 18 months after submission

I am aware that imposing an embargo reduces submitter benefits for reduced pricing purchases, and "Release immediately" is associated with cost benefits for purchasing additional samples.

Overview of Genetic Information for Samples to be Banked:

NINDS HUMAN GENETICS DNA AND CELL LINE REPOSITORY



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MEDICAL RESEARCH

a. Known genetic information prior to sample ascertainment:

	Present	Absent	Unknown	Please specify genetic syndrome and/or known mutations:
Known Genetic Syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Known Mutations in DNA	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

b. Will the samples be screened for known mutations: yes no

If yes, please indicate mutations to be screened: _____

Subjects and Study Information:

1. Is this a case/control study? Yes No

If yes, please answer the following:

- a.** How many cases? Next 12 months _____ Entire Project _____
- b.** How many controls (population + spousal)? Next 12 months _____ Entire Project _____

2. Is this a family-based study? Yes No

If yes, please answer the following:

- a.** Describe family structure used to identify families for study (e.g. proband & 1st degree relatives; trios of two parents & affected child; sibling pairs; extended family): _____

- b.** Total number of affected individuals to be ascertained:
Next 12 months _____ Entire Project _____

- c.** Total number of unaffected family members to be ascertained:
Next 12 months _____ Entire Project _____

- d.1** 1st degree relatives of affected individuals:
Next 12 months _____ Entire Project _____

- d.2** Extended family members, including spouses that are not 1st degree relatives of affected individuals:
Next 12 months _____ Entire Project _____

- d.** Total number of families to be ascertained: Next 12 months _____ Entire Project _____

- b.1** Number of families with 1 affected member:
Next 12 months _____ Entire Project _____

- b.2** Number of families with 2 affected members:
Next 12 months _____ Entire Project _____

- b.3** Number of families with ≥ 3 affected members:
Next 12 months _____ Entire Project _____

3. If your study does not fit either of the categories above, please describe and enumerate the subjects that will be submitted?

- a.** How many cases? Next 12 months _____ Entire Project _____
- b.** How many non-cases? Next 12 months _____ Entire Project _____
- Please describe these individuals _____

4. Is this study part of a clinical trial? Yes No

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If yes, please describe study design, therapeutic intervention, number of subjects, length of trial and additional phenotypic/clinical information, to be obtained (attach separate sheet).

Submitter Benefits:

For blood submissions you are entitled to 20ug of DNA per unique submission accepted for clinical data. For the skin biopsy submissions you are also entitled to 1 ampoule of fibroblasts per unique submission accepted for clinical data.

Please indicate your preference (select one):

1. Please send to PI or Study Coordinator (please specify which) at the address above
2. Please send to a collaborator:

Name: _____ Email: _____ Phone: _____

Shipping Address: _____

For 1 or 2 please indicate how frequently you prefer to receive DNA shipments (select one):

- Please send DNA in batches of at least 10 samples.
- Please send DNA samples immediately as they become available (shipments may include only one sample).
3. Please store to be requested at a later date
4. I elect to forego the opportunity to receive back-in-kind samples

Please mark all that apply:

1. I have received IRB approval to submit samples to the NINDS Repository. COPY OF YOUR APPROVED CONSENT MUST ACCOMPANY THIS REQUEST.
2. I am submitting from a site in the United States or Canada and I will transfer CDE information to Coriell electronically using the Repository's electronic data entry system, as required, when the sample is submitted.
Or
 I am submitting from a site outside the United States or Canada and I will submit the CDE information by fax when sample is submitted.
Or
 I am submitting from a site outside the United States or Canada and I elect to transfer CDE information to Coriell using the Repository's electronic data entry system.
Or
 This is a large project and I would like to utilize an alternative electronic data transfer system that is custom-designed for my project**.

** For such projects no samples can be submitted until the terms of sample and data submission have been approved by the NINDS Repository Project Officer.

3. I am aware that to promote sharing I am required to report all publications which refer to a given sample or sample set from the NINDS Repository when published, noting sample or catalog numbers in the publications (send email to ninds@coriell.org).
4. I will not submit duplicate subjects/samples from my study or other studies.
5. I have reviewed the Submitter's Guide and the Frequently Asked Questions (FAQs) section of the NINDS Repository Website; see <http://ccr.coriell.org/ninds>, under **Tools** on the right.
6. I would like to be listed on the website Acknowledgment Page <http://ccr.coriell.org/Sections/Collections/NINDS/Contributors.aspx?PgId=188&coll=ND> as a submitter to the NINDS Repository.

By signing below, I agree to abide by the regulations of the NINDS Repository.

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SUBMIT TO:

NINDS Repository
ninds@coriell.org
Fax: 856-966-5067

Signature, Investigator

Date

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