

NIGMS HUMAN GENETIC CELL REPOSITORY

SUBMISSION FORM – INVESTIGATORS

Please check or complete all applicable items. Please also attach any clinical descriptions, case histories, medical records, diagnostic test/laboratory reports or clinic summaries that support the diagnosis of this individual and any affected family members (if available).

Submitting Investigator: _____

Diagnosis: _____

OMIM #: _____

Disease Status: Affected Unaffected Carrier At Risk Unaffected Family Member

Subject ID Number: _____

Date of Sample Collection: / /

Age at Sample Collection (*if fetal tissue, gestational age in weeks*): _____

Days Weeks Months Years

Is this individual still living? Yes No Don't Know

If deceased, age at death: _____

Days Weeks Months Years

Sex: Male Female Ambiguous

Race (please check all that apply):

American Indian/Alaskan Native White Other _____

Asian Native Hawaiian/Other Pacific Islander

Black/African American Unknown

Ethnicity: Hispanic Non-Hispanic Unknown

Ancestry: (e.g. Italian, Nigerian, Mexican, German-Japanese, etc): _____

Source of Clinical Information: (please attach copies of reports/summaries/records)

- Physical Exam Medical Records Genetics Clinic Report Specialist Report
 Primary Care Physician Report Autopsy Record Other: _____

Family History Information:

Is there a family history of this condition? Yes No Don't Know (*please attach pedigree*)

If no pedigree, please describe the relationship of the sample donor to the other affected individuals. Please also briefly describe the phenotype(s) of the affected family member(s):

Have samples from other family members been submitted to the NIGMS Repository or to another Coriell repository?

- Yes No Don't Know

If yes, please list the relationship to this sample. If known, please also list the Coriell Repository ID # OR the submitter's name and approximate date(s) of submission for each family member:

Literature References:

Has this family/individual been reported in the medical literature? Yes No Don't Know

If yes, please list the PubMed ID #, citation (Journal, First Author, Year, Volume and Pages) or any other available information:

Sample Information:

- Sample Type: Peripheral Blood Skin Biopsy Solid Tissue Biopsy (site): _____
 Other: _____

Culture Type: Fibroblast Lymphoblast Amniotic Fluid Chorionic Villus

Differentiated Other: _____

For cell cultures, date originally established: ____/____/____

Passage # of culture: ____ Population doubling level: ____

Culture medium: _____

Serum (Type / %): ____ / _____

Additives (antibacterial/antifungal): _____

Other required nutrients? No Yes (please describe): _____

SPECIAL INSTRUCTIONS FOR GROWTH, HANDLING, OR FREEZING:

Consent:

Documentation that samples were collected with appropriate informed consent must accompany the submission:

For submitters at institutions with IRBs, an **unsigned** copy of the consent form approved by the institution's IRB

For submitters **not** at an institution with an IRB, a **signed** copy of the NIGMS Human Genetic Cell Repository Informed Consent Form

For existing cell lines, a **signed** copy of the NIGMS Human Genetic Cell Repository Informed Consent Form for the Transfer of Existing Specimens **OR** a blank copy of the consent form used by your institution at the time of sampling must accompany the submission.

Release and Permissions:

The cells and/or DNA derived from submitted samples may be distributed to scientists for many different types of research. The cells from submitted samples may also be used to create modified cell lines or may be reprogrammed to create induced pluripotent stem (iPS) cells to advance research in stem cell biology.

Scientists may use sample(s) submitted to the NIGMS Human Genetic Cell Repository ("NIGMS Repository") to study the sample donor's DNA and may share what they learn with other scientists. Data resulting from the use of submitted samples may be used in a research publication. In that event, the sample donor's name or other personally identifying information will not be included, as this information is not available to the scientists. The sample donor will not be provided with any specific information or results generated from research using

his/her specimen. However, there is a small possibility that the sample donor could learn that a sample described in research came from him/her and indirectly learn information about his/her sample.

If the sample donor informs me that he/she no longer wish to have his/her sample(s) in the NIGMS Repository, I may contact the NIGMS Repository by phone (856-757-4822) or by email (NIGMS@coriell.org) and request that the donor's remaining undistributed sample(s) and accompanying clinical information be withdrawn from the NIGMS Repository. However, it will not be possible to destroy samples and information that have already been distributed to researchers, and it will not possible to remove any mention of my sample(s) in publications.

The NIGMS Repository does not store the sample donor's name or any other personally identifying information. Therefore, any request for sample withdrawal must be made through me. As the investigator sending the donor's sample to the NIGMS Repository, only I will have the link between the sample donor's identity and his/her sample. I understand that a sample donor will be able to withdraw his/her sample ONLY if I maintain the link between the donor's name and the Sample ID Number(s) submitted to the NIGMS Repository.

I agree NOT to share with anyone the link between the NIGMS Repository catalog identification number and personally identifying information from the donor of the sample being submitted to the NIGMS Repository.

I understand that no financial compensation or medical benefits will be extended to the individual from whom the sample was collected or to the sample submitter.

I hereby grant permission for cells from this sample to be stored in the NIGMS Repository and for progeny cells, derived DNA and other products (such as iPS cell lines or RNA) to be distributed to qualified investigators in academic or commercial laboratories. Scientists are strictly prohibited from distributing the cell lines directly derived from NIGMS Repository samples, or material directly isolated from them, in commercial products or services. However, scientists may use information learned from studies on the sample(s) to develop commercial products or services. (See the NIGMS Human Genetic Cell Repository Material Transfer Agreement (MTA) or visit <https://catalog.coriell.org/1/NIGMS/How-to-Order> for provisions regarding distribution of materials derived from submissions.)

I certify that none of the blood samples, biopsies or cell cultures submitted to the NIGMS Repository has been obtained from a live fetus, defined by the presence of a pulse, circulation, and other vital signs.

To encourage storage of valuable cell cultures in the NIGMS Repository, provision has been made for delayed release of cell lines or DNA to other investigators if the submitter so desires.

Release cell lines/DNA **ONLY** to submitter or designee during the first year.

No restriction on the release of cell lines/DNA to other investigators is requested.

Submitting Investigator's Name: _____

Submitting Investigator's Address: _____

Telephone #: _____ Fax #: _____

E-mail: _____

Submitting Investigator's Signature: _____ Date: / /

Sample Submission Checklist:

- Completed NIGMS Repository Submission Form
- Signed NIGMS Repository Informed Consent/Assent Form OR unsigned copy of your IRB-approved Informed Consent/Assent document
- Completed NIGMS Repository Clinical Data Elements Form
- Copies of available pedigrees, lab reports, summaries, records or other documentation
- Sample (email NIGMS@coriell.org or call 856-757-9690 for questions about collecting or shipping samples)
- Email NIGMS@coriell.org or call 856-757-9690 to notify NIGMS Repository of the sample shipment date

Ship sample and required paperwork Priority Overnight for arrival Monday-Friday to:

Project Manager, NIGMS Repository
Coriell Institute for Medical Research
403 Haddon Avenue
Camden, New Jersey 08103

Contact the NIGMS Repository:

403 Haddon Avenue
Camden, New Jersey 08103
Telephone: (856) 757-9690
Email: NIGMS@coriell.org

For Shipping Records:

The carrier (Federal Express, DHL, O Airborne, etc.) _ _____

The shipment was sent on: _ _____ by _ _____.