CORIELL INSTITUTE
FOR MEDICAL RESEARCH

NIGMS HUMAN GENETIC CELL REPOSITORY
SUBMISSION FORM – DIRECT TO PATIENT

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).

Name of Donor: _____

Diagnosis: _____

OMIM # (if known): _____

Disease Status: ☐ Affected ☐ Unaffected Carrier ☐ At Risk ☐ Unaffected Family Member

Date of Sample Collection: _____ / _____ / _____

Age at Time of 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 time of death: _____

☐ Days ☐ Weeks ☐ Months ☐ Years

Sex: ☐ Male ☐ Female ☐ Other

Race (please check all that apply)**:**

☐ American Indian/Alaskan Native ☐ Native Hawaiian/Other Pacific Islander ☐ Other _____

☐ Asian ☐ Unknown

☐ White

☐ Black/African American ☐ Not Reported

Ethnicity: ☐ Hispanic ☐ Non-Hispanic ☐ Unknown ☐ Not Reported

Ancestry: _____

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

If yes, please describe the relationship of the sample donor to the affected family members. Please also briefly describe the clinical symptoms of the affected family member(s):

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

☐ Yes ☐ No ☐ Don't Know

If yes, please list the relationship to this person. If known, please also list the 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 (please select one):

☐ Peripheral Blood ☐ Skin Biopsy

☐ Solid Tissue Biopsy (please indicate site of biopsy – arm, leg, etc.): _____

☐ Other: _____

Consent:

A signed copy of the NIGMS Human Genetic Cell Repository Informed Consent Form 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 no longer wish to have his/her sample(s) in the NIGMS Repository, he/she may contact the NIGMS Repository staff by phone (856-757-4822) or by e-mail (NIGMS@coriell.org) and request that the 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.

I understand that no financial compensation or medical benefits will be extended 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 your submission.)

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.

Name of Donor:_____

Signature:_____

Date:_____

Sample Submission Checklist:

☐ Completed NIGMS Repository Submission Form

☐ Signed NIGMS Repository Informed Consent/Assent Form

☐ 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, 0 Airborne, etc.) _____

The shipment was sent on: _____ by _____.