

# BPAN WARRIORS

CONNECT | COLLABORATE | CURE



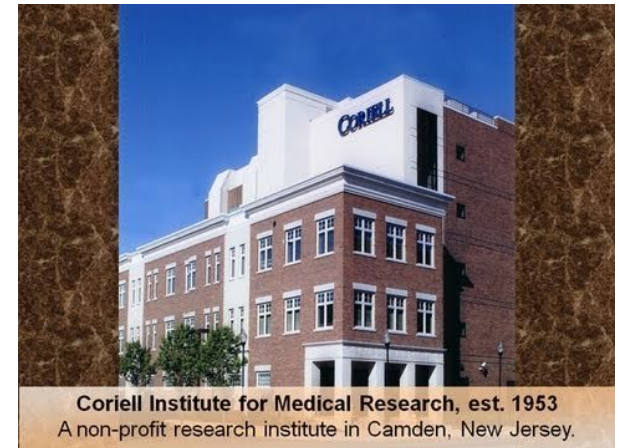
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BPAN RESEARCH AND COLLABORATIVE EXCHANGE (R.A.C.E.)  
COLLECTION AT THE NIGMS REPOSITORY – CORIELL INSTITUTE

# ABOUT THE CORIELL INSTITUTE

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- The Coriell Institute for Medical Research is an independent, not-for-profit research organization whose mission is to accelerate scientific discovery by providing the highest quality genetic resources.
- The Coriell Institute:
  - Houses some of the world's largest biobanks
  - Distributes cell lines and DNA worldwide
  - Conducts research on stem cells, genetic variation, cancer, and the utility of personalized medicine



# WHAT IS A CELL REPOSITORY

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A collection of well-characterized, high-quality human cells for use in biomedical research. The NIGMS Human Genetic Cell Repository at the Coriell Institute in Camden, NJ was established in 1972. The repository now contains over 10,000 cell lines. The collection contains cell lines and DNA derived from cells that have been acquired from individuals with inherited diseases, from apparently healthy individuals, and from individuals of diverse geographic origins.

Through partnerships with federal, nonprofit, and private organizations, Coriell offers the world's most diverse collection of biological samples:

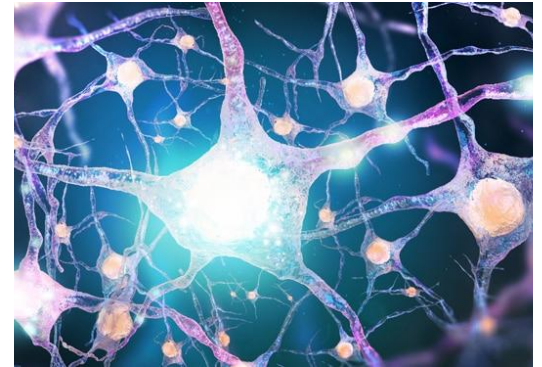
- [NIGMS Human Genetic Cell Repository](#): Sponsored by the National Institute of General Medical Sciences (NIGMS)
- [NINDS Human Genetics DNA and Cell Line Repository](#): The National Institute of Neurological Disorders and Stroke (NINDS)
- [NIA Aging Cell Repository](#): Sponsored by the National Institute on Aging (NIA)
- [NHGRI Sample Repository for Human Genetic Research](#): The National Human Genome Research Institute (NHGRI)
- [Allen Cell Collection](#)
- [American Diabetes Association, GENNID Study](#): Genetics of non-insulin dependent diabetes mellitus, NIDDM
- [The Autism Research Resource](#)
- [CHDI Repository](#): The HD Community BioRepository supported by CHDI
- [USIDNET Repository](#): The US Immunodeficiency Network
- [CDC Cell and DNA Repository](#): The Genetic Testing Reference Material Coordination Program of the Centers for Disease Control and Prevention (CDC)
- [NEI-AREDS Genetic Repository](#): National Eye Institute Age-Related Eye Disease Study
- [J. Craig Venter Institute Human Reference Genome \(HuRef\)](#)

# WHAT IS A CELL REPOSITORY

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The NIGMS Human Genetic Cell Repository (“NIGMS Repository”), a research resource supported by the National Institutes of Health, collects, stores, and distributes cell cultures, DNA samples and associated de-identified data from individuals with many kinds of disorders, from unaffected family members of these individuals, and from other healthy people.

The purpose of this collection is to make specimens available for use in research and teaching and as reference material for use in clinical genetics laboratories. ***Submission of samples to the NIGMS Repository may result in valuable research materials that can be used by scientists to better understand normal and disease processes, and to develop new diagnostic tests, new treatments, and new ways to prevent diseases.***



# STEPS FOR DONATING BLOOD SAMPLES

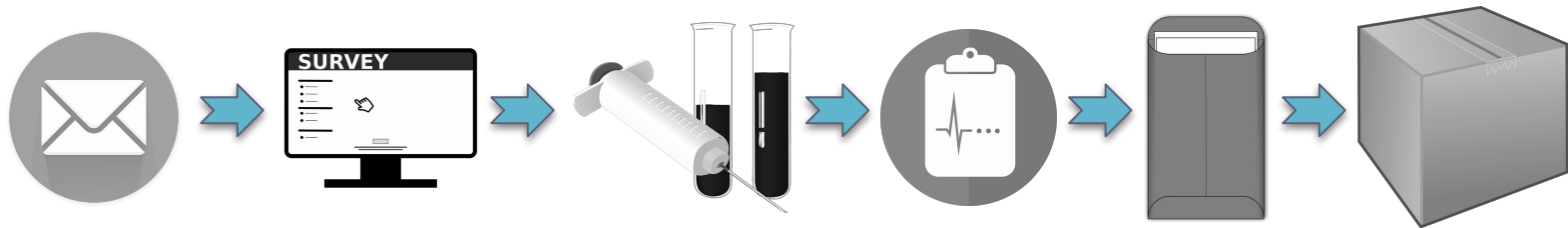
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To donate your sample to the NIGMS Human Genetic Cell Repository, you or your child must have an inherited genetic disease or chromosome abnormality.

- Request more information via BPAN R.A.C.E BioRepository Registration: [info@bpanwarriors.org](mailto:info@bpanwarriors.org)
- Complete optional BPAN R.A.C.E BioRepository Registration (allows BPAN R.A.C.E. to facilitate with ongoing MTAs, assess community engagement and reach, and ensure that biorepository is robust and reflective of patient population); ***this is purely voluntary and is not a prerequisite for providing a sample.***
- Instructions for blood collection and MTAs will be provided
- Complete the informed consent, submission and clinical data summary forms
- Have blood drawn
- Use the prepaid FedEx label to return the kit with your sample and completed paperwork

Assigned BPAN R.A.C.E BioRepository Manager:

Sherryann I. Wert, MA (856) 757-9730



# STEPS FOR DONATING FIBROBLASTS AND/OR OTHER BIO SAMPLES


Plan biopsy collections for Monday through Thursday. Link to submission instructions:

[Human Tissue Biopsy Submission Instructions](#)


Items Provided in Biopsy Kit	Items Not Provided in Biopsy Kit
Conical tube (15 ml) with serum-free Ham's F12 medium containing antibiotics	Anesthetics and syringes
Bubble pouch to hold tube, SAF-T-Pak clear plastic inner biohazard bag with absorbent sheet, and outer Tyvek® bag	Surgical gloves
Inner Styrofoam box and outer cardboard box	Disinfectants: 70% alcohol or alcohol swabs and Betadine® or Hibiclens®
Labels: Biological Substance Label, Do Not Delay Biologicals, Fragile Handle with Care	Biopsy punch (3 mm)
NIGMS HGCR Submission Form, Informed Consent Form, Assent Form (if applicable), and Clinical Data Elements Form	Surgical instruments
NIGMS HGCR Biopsy Submission Instructions and instructions for how to complete the required paperwork	Bandages and sterile gauze pads
Pre-paid FedEx air bill pre-addressed to Coriell	Parafilm®
	Ice pack

# IMPORTANCE OF CENTRALIZED BIO SAMPLES

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- Working together to create a centralized and easily accessible biobank used for research
- A biobank can contain DNA, cell lines, and stem cells made from the blood or tissue of a person affected by a genetic disorder
- Knowledge is power! The more that is known about a genetic disease, the higher the chances of finding new treatments

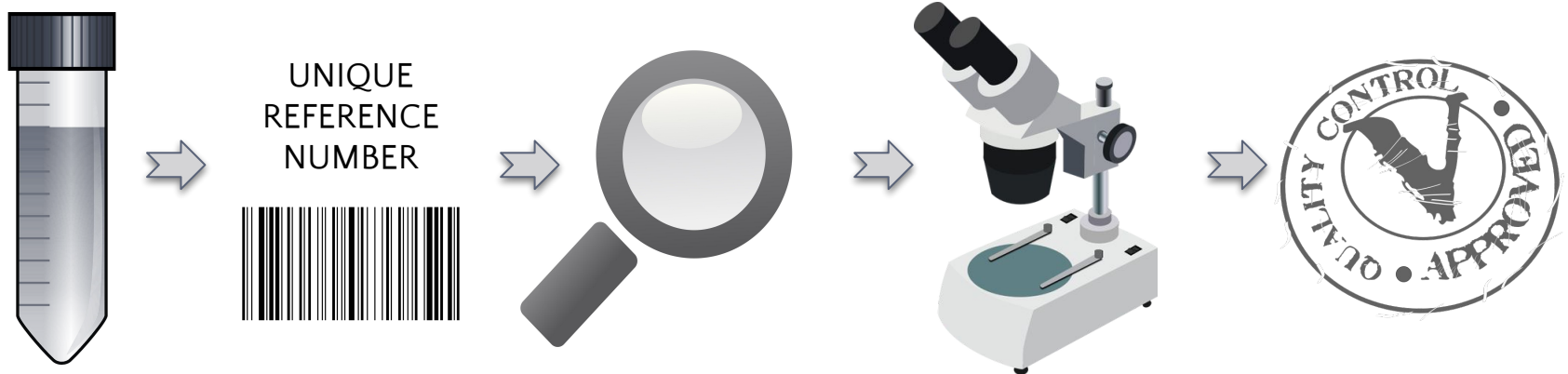


Many hospital systems are moving toward centralized sample storage and management. Instead of storing small sample collections in each clinic for department-specific research needs, samples from multiple sites are sent to a centralized biobank facility for processing, storage and tracking. With centralization, organizations can establish and implement unified standard operating procedures (SOPs) to ensure quality and maintain the sample data that is critical to research studies. The central facility then reviews and fills requests for access to the samples from groups within or outside the organization.

# ACCESS TO SAMPLES

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Each sample is given a unique reference number and processed according to standard Repository protocols. Lymphoblastoid cell lines are established from blood samples, and fibroblast cell lines are established from skin biopsy specimens. All incoming samples, including existing cell lines, undergo rigorous quality control procedures to ensure they are uncontaminated and viable. Before being made available to the scientific community, all samples must pass the quality control protocols and be reviewed by the Repository's staff.





# FAQ'S

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- **I already donated sample to another institution, why do I need to donate again?** With the help of generous donors like you, the NIGMS Repository at the Coriell Institute has been able to create an internationally recognized research resource of unparalleled scope. Samples from the repository have been used in over 7,000 scientific publications and have been utilized by scientists in more than 50 countries. The BPAN R.A.C.E. collection at the Coriell Institute will provide greater accessibility to pre-screened, catalogued patient samples, without the lengthy time frames associated with accessing private and academic biological samples.
- **Can I have my samples from another institution transferred to the Coriell Institute?** With patient consent, the Coriell Institute will initiate the transfer of existing iPSC lines and certain tissue specimens from the original institution. Please note that this does not guarantee that outside institutions will grant access to existing patient samples. The materials transfer process may take many months and may have to go through formal review by Institutional Review Board.

Additionally, existing blood samples cannot be transferred from an outside institution (not cost effective), however patients may request a blood collection kit, with prepaid postage for submission of a new blood sample to the Coriell Institute.

# FAQ'S CONTINUED

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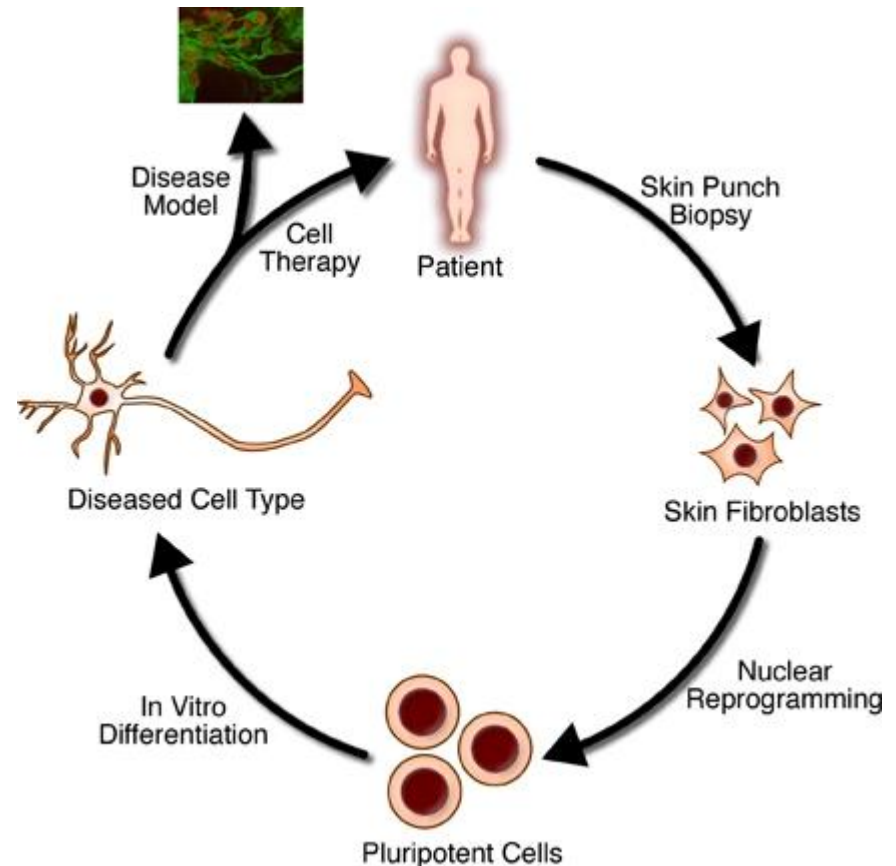
- **What is the safety and de-identification process?** At Coriell, the privacy and confidentiality of each donor is a priority. The following measures to protect the privacy of donors are taken:
  - Assign a code number to each sample
  - Remove donor's name and any personally identifying information
  - Follow strict guidelines that forbid the repository from distributing ANY personally identifying information to recipients of materials generated from donated samples
  - A Certificate of Confidentiality from the National Institutes of Health—protects the repository from being compelled by federal, state or local court order to disclose your participation without your written consent In the future, if you decide that you no longer wish to participate, you may contact the NIGMS Repository staff ([NIGMS@coriell.org](mailto:NIGMS@coriell.org)) and request that your remaining undistributed sample(s) and clinical information be withdrawn.

# FAQ'S CONTINUED

- **What is an iPSC line; why is this important?**

Induced Pluripotent Stem Cells (iPSC) are derived from skin or blood cells that have been reprogrammed back into an embryonic-like pluripotent state that enables the development of an unlimited source of any type of human cell needed for therapeutic purposes. iPSCs offer a unique chance to model human disease and are already being used to make new discoveries about premature aging, congenital heart disease, cancer, and more.

- **What are the costs associated with donating a blood sample?** Coriell covers the cost of shipping. It is recommended that your sample be collected during a scheduled doctor's visit. The Coriell Institute can reimburse you up to \$40 if you need to pay to have your blood drawn at a draw station, like Quest or LabCorp.



# Links

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- [BPAN Warriors Website](#)
- [BPAN Warriors Slide Deck](#)
- [Coriell Institute Website](#)
- [Informed Consent NIGMS](#)
- [Informed Consent For Transfer Of Existing Specimens](#)
- [NIGMS Human Genetic Cell Repository Submission Form](#)
- [Human Tissue Biopsy Submission Instructions](#)

