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INTEGRATED DISEASE REGISTRY AND REPOSITORY SERVICES NOW AVAILABLE THROUGH THE CORIELL INSTITUTE AND PATIENTCROSSROADS

Patient advocacy organizations and research investigators can now take advantage of a new integrated registry and repository resource to further advance rare disease research. Blood or tissue samples donated to the NIGMS Human Genetic Cell Repository at the Coriell Institute for Medical Research can be linked to de-identified clinical data in patient registries built by PatientCrossroads. The samples and corresponding clinical information are then made available to the international scientific community for use in basic research, gene discovery and the development of potential treatments.

Key features of the integrated registry and repository solution offered by Coriell Institute and PatientCrossroads include:

- All registry/repository participant data is accessible through a global unique identifier, protecting privacy;
- Registry/repository data is collected in a single location, minimizing the time burden on participating patients and families;
- Cell lines and DNA established from donated blood or tissue samples undergo rigorous quality control measures, ensuring availability of high quality biomaterials to the international scientific community;
- Scientists using the samples can access current and past information about sample donors, resulting in an enhanced understanding of the disease course over time;
- Transfer of collections from existing research programs, including existing cell lines or registry data, can be achieved to ensure future availability of established resources.

Participating patient advocacy organizations are already benefitting from this proven, cost-efficient, registry-repository partnership. The Congenital Muscle Disease Collection, a collaboration between Cure CMD, the Congenital Muscle Disease International Registry (CMDIR), and the NIGMS Repository was recently established to help advance research and invest in the future of CMD therapy development.

Patient advocacy organizations interested in setting up integrated registry and repository services, and research investigators interested in access to samples with registry data should contact nigms@coriell.org.

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About the NIGMS Human Genetic Cell Repository and Coriell Institute for Medical Research

The National Institute of General Medical Sciences (NIGMS) Human Genetic Cell Repository provides the international research community with cell lines and DNA from individuals with a variety of genetic diseases and chromosomal abnormalities (www.ccr.coriell.org). The repository is supported by contract # HHS-N-263-2009-00026-C from the National Institute of General Medical Sciences, one of the National Institutes of Health, to the Coriell Institute for Medical Research.

Coriell Institute for Medical Research (www.coriell.org) is an independent, non-profit biomedical research center based in Camden, New Jersey. Founded in 1953, the Institute is dedicated to unlocking the genetic code of human disease. Coriell is a pioneer in genomics, examining the utility of genetic information in clinical care through the Coriell Personalized Medicine Collaborative® (CPMC®) research study (www.cpmc.coriell.org). Coriell is also exploring the promise of induced pluripotent stem cells – stem cells created from skin or blood – and their role in disease research and drug discovery. Additionally, Coriell continues to be recognized as the world's leading biobank, distributing biological samples, and offering custom research and biobanking services to scientists around the globe.

About PatientCrossroads

PatientCrossroads (www.patientcrossroads.com/) provides registry systems that connect communities of people with rare diseases and scientists studying those conditions. The organization offers software, technology, management and data curation services. To support rare disease groups that do not have patient registries, the Office of Rare Diseases Research at the National Institutes of Health (NIH) and PatientCrossroads have launched the Global Rare Disease Registry and Data Repository.