New Project Will Improve Newborn Screening for Heart Disease Throughout New England

Matt Gianino
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DURHAM, N.H. – A new project from the University of New Hampshire Institute on Disability (IOD) will address regional gaps in newborn screening for critical congenital heart disease (CCHD). The New England CCHD Newborn Screening Project is funded by a three-year, $900,000 grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, and it is affiliated with the New England Genetics Collaborative.

For infants born with CCHD, early diagnosis and treatment are key to supporting long-term health, and screening for CCHD as part of newborn genetic screening plays an essential role in the diagnostic process. In New England, implementing CCHD screening as part of regular newborn screening is particularly challenging for several reasons, including staffing limitations at public health agencies and birthing facilities to maintain new programs; lack of education for healthcare providers and families; and wide geographic distribution of birthing facilities, the pediatric specialists providing services, and the families receiving services.

In order to address these challenges, the Northeast CCHD Newborn Screening Collaborative aims to enhance existing connections among state public health departments and birthing facilities and to share resources and expertise in developing CCHD newborn screening protocols, educational materials, programs, and evaluation in Maine, New Hampshire, Vermont, Rhode Island, and Connecticut. Further, these resources will be used to ensure that families have access to critical diagnostic and treatment services, regardless of how far away they live from major cities in the region.

“We have a unique opportunity to support the development, dissemination, and validation of screening protocols and infrastructure specific to CCHD, and we’re excited to collaborate with our New England partners,” said Monica McClain, project director and research associate professor at the IOD.

As part of this project, each of the five state public health departments will establish roles for collecting screening data, monitoring and quality assurance of screening, and incorporating screening results into existing registries. The project is also working with nine regional birthing facilities: Catholic Medical Center, Manchester; Concord Hospital, Concord; Dartmouth-Hitchcock Medical Center, Lebanon; Elliot Hospital, Manchester; Hartford Hospital, Hartford, Conn.; Maine Medical Center, Portland, Maine, and affiliated sites; Wentworth-Douglas Hospital, Dover; Women & Infants Hospital, Providence, R.I.; and Yale-New Haven Hospital, New Haven, Conn. The birthing facilities will conduct CCHD screening as part of their current newborn screening programs and report results.
For more information, visit www.iod.unh.edu/Projects/newengland_cchd.

The Institute on Disability at the University of New Hampshire was established in 1987 to provide a coherent university-based focus for the improvement of knowledge, policies, and practices related to the lives of persons with disabilities and their families. Its mission is to strengthen communities to ensure full access, equal opportunities, and participation for all persons.

The University of New Hampshire, founded in 1866, is a world-class public research university with the feel of a New England liberal arts college. A land, sea, and space-grant university, UNH is the state's flagship public institution, enrolling 12,200 undergraduate and 2,300 graduate students.

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