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Individuals With Genetic Disorders To Receive Enhanced Services And Supports Through New Grant

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DURHAM, N.H. – Since newborn screening for genetic disorders like cystic fibrosis and sickle cell disease has become a standard public health practice, more and more genetic diagnoses are being addressed early in life. In view of this, the Institute on Disability, in partnership with the New Hampshire Institute for Health Policy and Practice at the University of New Hampshire (UNH) and the Dartmouth-Hitchcock Medical Center Department of Pediatrics, Division of Medical Genetics, intends to enhance the services and supports for individuals with genetic disorders through a new grant.

The New England Regional Genetics and Newborn Screening Collaborative (New England RC) grant, awarded by the U.S. Department of Health and Human Services in June, will address the needs of individuals, agencies, and health care providers who interact with and treat individuals with genetic disorders and their families. The $4 million grant, to be received over five years, will provide technical assistance, accessible information, educational opportunities, and other support for public health officials, consumers, advocates, primary and specialty health care providers, and other agencies and individuals who serve as formal and informal supports to those with genetic disorders throughout the New England region.

As part of the project, the New England RC will encourage collaboration by establishing a Regional Coordinating Center at the Institute on Disability at UNH. The primary goal of the New England RC is to assure that individuals with genetic disorders and their families have access to quality care, appropriate genetics expertise, and information that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care. One activity of the Regional Coordinating Center will be to organize and support six state teams, assuring that resources to solve local needs are readily available to all. The state teams will facilitate access to genetics services and technology, serve as focal points for genetics education and information, and examine and address ethical, legal, and social issues, as well as current public policy and public health infrastructure.

To learn more about the New England RC, contact Amy Philbrick Schwartz, project coordinator and associate director and clinical assistant professor, New Hampshire Institute for Health Policy and Practice, at (603)862-5099 or amy.schwartz@unh.edu.

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 advance policies and systems changes, promising practices, education, and research that strengthen communities to ensure full access, equal opportunities, and participation for all
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