



## Genetics Collaborative Awards \$100K For Innovative Projects

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DURHAM, N.H. - For the third year, the New England Genetics Collaborative (NEGC), housed at the University of New Hampshire's Institute on Disability, has selected proposals for funding as part of its Innovative Projects program. This program encourages short-term creative projects that meet emerging needs in the field of genetics. Proposal requirements include sponsorship by one of the NEGC's collaborative council members and a maximum budget of \$30,000. Of the nine proposals received, three contracts were awarded:

- **Developing Parent-Provider Partnership Plans for Children Referred to Specialty Care**, submitted by Dr. Chris Stille of the University of Massachusetts Medical School. This project will further develop and pilot test a care planning tool which will increase parents' abilities to share medical information and plan care with primary care physicians and specialists. Project staff members anticipate seeing improvements in three areas: parents' management of their children's conditions, primary physician/specialist co-management, and ultimately better clinical health outcomes.
- **Development and Initiation of a New England Birth Defects Consortium**, submitted by Stephanie Miller of Dartmouth Medical School. All New England states currently operate state-wide birth defects programs, but routine collaboration on program goals and objectives has been limited. Also, small population size often prevents individual states from applying for grants where more data is required. This project will form a regional consortium to facilitate project and data collection coordination among New England birth defect registry programs. The aim of the consortium is to improve services for infants and children with birth defects by promoting regional collaboration in surveillance data sharing, birth defects research, prevention activities and health care quality improvement.
- **The Personal Transition Health Plan Project**, submitted by Susan Waisbren, Children's Hospital Boston. For adolescents with metabolic and/or genetic disorders, a smooth and successful transition from pediatric to adult health care is especially important to promote uninterrupted treatment. The long-term goal of this project is to develop and pilot a practice model that ensures that every adolescent and young adult patient seen at a genetics or metabolic clinic has thought about and documented a plan for ongoing health care. Fact sheets and a transition checklist will be developed, and college interns will assist patients in completing the forms.

Funded by a federal cooperative agreement from the Health Resources and Services Administration (HRSA), the NEGC promotes collaborations between the medical community, public health professionals, educators, advocates, and families in all six New England states. The NEGC partners with the Institute for Health Policy and Practice at UNH and the Dartmouth-Hitchcock Medical Center, Department of Pediatrics, Division of Clinical Genetics to enhance the services and supports for individuals with genetic disorders.

For more information about the NEGC Innovative Projects Program, contact Amy Schwartz, project manager, at (603) 862-2962 or [amy.schwartz@unh.edu](mailto:amy.schwartz@unh.edu), or Karen Smith, project coordinator, at (603) 862-3454 or [karen.smith@unh.edu](mailto:karen.smith@unh.edu). For more information about the NEGC and future funding initiatives, visit [www.negenetics.org](http://www.negenetics.org).

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 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 11,800 undergraduate and 2,400 graduate students.

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