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IOD's Genetics Collaborative Awards Additional $100k For Small Projects

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September 15, 2008

DURHAM, N.H. - The New England Genetics and Newborn Screening Collaborative (NEGC), housed at the University of New Hampshire's Institute on Disability, has for the second year awarded a total of $100,000 in contracts as part of its Innovative Small Projects program. This annual funding 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 proposals received, five contracts were awarded:

- "Patient-as-Teacher Project," submitted by Dr. Mark Korson of Tufts Medical Center in Boston. This project will enhance the already successful Metabolic Outreach Service, which provides expert consultation to academic medical centers, by incorporating personal perspectives directly from patients and their families. Originally funded during the first set of Innovative Small Projects, this project will continue to develop a registry of speakers and record presentations for greater distribution.

- "Making the Move: Mapping YOUR Best Route to Adult Sickle Cell Care," submitted by Bill Kubicek of Next Step in Cambridge, Mass. This project also funded during the first set of Innovative Small Projects received additional funding to continue implementing a replicable model of educating young adults with Sickle Cell disease about making the transition to the adult health care system. This project will focus on engaging young adults in their curriculum, a tool that has been successful in the past for young adults with other diseases/conditions.

- "Thyroid Dysfunction: Long Term Follow-Up of Very Low Birth Weight (VLBW) and Extremely Low Birth Weight (ELBW) Infants," submitted by Dr. Chanika Phornphutkul of Rhode Island Hospital in Providence, R.I. This project will conduct a retrospective review of medical records to determine the incidence of hypothyroidism and transient hypothyroidism in VLBW and ELBW infants. Project findings could ultimately impact newborn screening protocols for these populations.

- "Meeting the Challenge of Identifying Urea Cycle Disorders by Newborn Screening," submitted by Dr. Margretta Seashore of Yale School of Medicine in Hartford, Conn. This project will conduct a retrospective analysis of the effectiveness of current newborn screening strategies for identifying and treating urea cycle disorders.

- "New England Connection for PKU and Allied Disorders (NECPAD) Implementation of Strategic Plan," submitted by Denise Queally and Donna McGrath of the New England Connection for PKU and Allied Disorders (NECPAD) in Milton, Mass. Originally funded during the first set of Innovative Small Projects to provide leadership training to young
adults with metabolic disorders, NECPAD will be strengthened through the hiring of a consultant to help implement a strategic plan.

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 Small Projects Program, contact Amy Schwartz, project manager, at (603) 862-2962 or amy.schwartz@unh.edu, or Karen Smith, project coordinator, at (603) 862-3454 or karen.smith@unh.edu. For more information about the NEGC and future funding initiatives, visit 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.

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