

ACMG NEWS

For Immediate Release

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ACMG is Awarded Five Year, \$12.5 Million Dollar Contract Renewal to Continue Important Efforts in Newborn Screening

BETHESDA, MD – Oct. 17, 2013 | ACMG was recently notified that it had been awarded a five-year extension of its NICHD contract for The Newborn Screening Translational Research Network (NBSTRN) Coordinating Center (www.nbstrn.org). The NBSTRN will continue its charge of improving the health outcomes of newborns with genetic or congenital disorders by means of an infrastructure that allows investigators access to robust resources for newborn screening research.

The grant, worth \$12.5 million, from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health will cover work to be completed through September 2018.

"We are thrilled to be able to continue our work for the next five years. We believe that the resources we have built are essential to the Newborn Screening community and we look forward to enhancing the tools in the next 5 years," said Michael S. Watson, PhD, FACMG, Project Director of the NBSTRN.

NBSTRN supports a number of research projects throughout the United States through assistance in accessing dried blood spots, enabling data collection, analysis and sharing for development of new technologies and treatments and fostering a community of collaborative research. These researchers are working to:

- Improve our understanding of the conditions that are in NBS or under consideration for addition to NBS,
- Pilot test new conditions in newborn screening
- Assess the role new technologies such as genome sequencing can play in newborn screening
- Identify the preferred technologies for newborn screening through comparative effectiveness research

In addition to helpful information for parents and the general public about newborn

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screening, the NBSTRN website (www.nbstrn.org) is the information portal for accessing all of the services available to investigators which include but are not limited to the:

- [R4S: Laboratory Performance Database](#)
- [VRDBS: Virtual Repository of Dried Blood Spots](#)
- [LPDR: Longitudinal Pediatric Data Resource](#).

For more information, please visit www.nbstrn.org.

About the Newborn Screening Translational Research Network Coordinating Center

The Newborn Screening Translational Research Network (NBSTRN) Coordinating Center provides resources for investigators engaged in newborn screening related research. This research includes new technology development, tools for developing the clinical history of heritable disorders, and new treatment development.

The NBSTRN is funded by a contract from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Institutes of Health (NIH) to the American College of Medical Genetics and Genomics. The NBSTRN works in collaboration with the Association for Public Health Laboratories (APHL), American Academy of Pediatrics (AAP), Genetic Alliance (GA), Health Resources and Services Administration (HRSA), National Library of Medicine (NLM), and Centers for Disease Control and Prevention (CDC).

For more information on the mission and scope of the work of the NBSTRN, visit www.nbstrn.org.

About the American College of Medical Genetics and Genomics and ACMG Foundation for Genetic and Genomic Medicine

Founded in 1991, the American College of Medical Genetics and Genomics (www.acmg.net) advances the practice of medical genetics and genomics by providing education, resources and a voice for more than 1600 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals. ACMG is the only nationally recognized medical organization dedicated to improving health through the practice of medical genetics and genomics. The College's mission includes the following goals: 1) to define and promote excellence in the practice of medical genetics and genomics and to facilitate the integration of new research discoveries into medical practice; 2) to provide medical genetics and genomics education to fellow professionals, other healthcare providers, and the public; 3) to improve access to medical genetics and genomics services and to promote their integration into all of medicine; and 4) to serve as advocates for providers of medical genetics and genomics services and their patients. *Genetics in Medicine*, published monthly, is the official ACMG peer-reviewed journal. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Find a Geneticist tool. The educational and public health programs of the American College of Medical Genetics are dependent upon charitable gifts from corporations, foundations, and individuals through the ACMG Foundation for Genetic and Genomic Medicine (www.acmgfoundation.org).

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