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Pioneering HHS HRSA Grant Funds Establishment of First National Newborn Screening Clearinghouse

WASHINGTON – September 16, 2009 – The nation’s first Newborn Screening Clearinghouse (NBSC), connecting millions of parents and healthcare providers with resources and information relevant to more than four million newborns screened annually, will be created through a \$3.75 million cooperative agreement from the U.S. Health and Human Services, Health Resources and Services Administration (HRSA), Genetic Services Branch. The project will span five years.

[Genetic Alliance](#) and the [National Newborn Screening and Genetics Resource Center](#) (NNSGRC) at the University of Texas Health Science Center at San Antonio, will develop the NBSC with the [Genetics and Newborn Screening Regional Collaborative Groups](#), [March of Dimes](#), the [Association of Public Health Laboratories](#) and many other partners.

For more than 40 years infants born in the U.S. have been screened for an increasing number of congenital conditions, yet parents are often unaware of the number and quality of screening their children received or how options may vary from state to state. The NBSC will increase awareness of newborn screening, and improve understanding and informed decision-making capacity of expectant and new parents, health professionals, industry representatives, and the public. The project will connect state and regional public health groups in these efforts and facilitate data and resource sharing. It will provide a central linkage location for access to informational resources and data on quality indicators of newborn screening. The NBSC will be responsive to emerging technologies and the public health challenges these technologies will present. It will also take advantage of newly established and promising communications technologies that allow just-in-time and point-of-service access for parents and providers alike.

“The National Newborn Screening and Genetics Resource Center is the robust core of the new NBSC,” said Bradford Therrell, Jr., Ph.D., director of NNSGRC. “The current national newborn screening data reporting system will be taken to the next level in this project. We look forward to collaborating with Genetic Alliance in the development of this resource.”

“The nation’s newborn screening (NBS) programs are a phenomenal, unsung, public health success,” stated Sharon Terry, president and chief executive officer of Genetic Alliance. “NBS offers an unparalleled opportunity to integrate electronic health technologies, data standards, data collection, and consumer-focused educational materials all in one coordinated system. Essentially every child in the nation is screened, and enters the healthcare system in a place where the system is working. The NBSC will allow for appropriate data transparency, integrated tools, technologies and education, and provide the basis for follow-up.”

“Newborn screening touches the lives of millions of families and hundreds of thousands of healthcare providers each year,” declared Natasha Bonhomme, NBSC project director and the vice president of strategic development at Genetic Alliance. “The NBSC partners’ goal is to transform information sharing within newborn screening in the interest of each child born in America. Parents will better understand which newborn screens are required and options for additional screening, while state newborn screening programs will receive needed support in their mission to serve the newborns of our country.”

The NBSC partners plan to develop the electronic and outreach components of the NBSC simultaneously. Terry serves on the Office of the National Coordinator’s Health Information Technology (HIT) Standards Committee, so development of the NBSC will model new HIT/exchange guidelines as they are created. Due to the consumer focus of Genetic Alliance, the project will balance privacy concerns and the informational needs of the public and providers. Therrell has served on both the American Academy of Pediatrics and American College of Medical Genetics Working Groups, defining current and future national activities in newborn screening.

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About Genetic Alliance

Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit <http://www.geneticalliance.org>.

About National Newborn Screening and Genetics Resource Center

The National Newborn Screening and Genetics Resource Center (NNSGRC) is a cooperative agreement between the Maternal and Child Health Bureau (MCHB), Genetic Services Branch and the University of Texas Health Science Center at San Antonio (UTHSCSA), Department of Pediatrics. The project is funded by the Health Resources and Services Administration (HRSA). The mission of the NNSGRC is to: 1) provide a forum for interaction between consumers, health care professionals, researchers, organizations, and policy makers in refining and developing public health newborn screening and genetics programs; and 2) serve as a national resource center for information and education in the areas of newborn screening and genetics. For more information, visit <http://genes-r-us.uthscsa.edu/>.