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Contact: Natasha F. Bonhomme  
202-966-5557 x 211  
nbonhomme@geneticalliance.org

## **Genetic Alliance Wins Multi-Million Dollar Newborn Screening Award Renewed Commitment to Run Nation's Newborn Screening Clearinghouse**

**Washington, DC (September 17, 2014)** - Genetic Alliance is pleased to announce receipt of a four-year cooperative agreement to maintain and build upon the nation's Newborn Screening Clearinghouse. This cooperative agreement builds upon the original award for the Newborn Screening Clearinghouse, obtained by Genetic Alliance in 2009. The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch funds this program, which will span 4 years.

Each year, nearly 4 million babies are born in the United States and receive newborn screening for serious, but treatable conditions. In 2011, after multiple beta iterations, Genetic Alliance fully launched Baby's First Test ([www.BabysFirstTest.org](http://www.BabysFirstTest.org)), a web portal to access newborn screening content from the local, regional, and national perspectives. Genetic Alliance will continue its efforts in providing the most up to date newborn screening information to expectant and new parents, families, healthcare providers, policymakers, and other stakeholders. "This nearly 3 million dollar award will allow the continuation of innovative awareness efforts as well as support a new evidence-based approach to evaluating newborn screening educational efforts," states co-principal investigator Natasha F. Bonhomme. She adds, "We are thrilled to continue our work with newborn screening partners across the country to improve public engagement in this critical public health program."

For the past 50 years, state departments of health have provided newborn screening for an increasing number of conditions. As the number of conditions screened increases, there is a growing need for public understanding of this system. "This next iteration of the Clearinghouse will focus on both raising awareness for newborn screening and best practices for educational initiatives," says Beth Tarini, MD, MS, Assistant Professor at University of Michigan and Co-chair of the Clearinghouse Steering Committee.

Stacy Hines-Dowell, DNP, APNG, Doctor of Nursing Practice with the Division of Genetics and Metabolism at Phoenix Children's Hospital, and Co-chair of the Clearinghouse Steering Committee affirms, "[t]his is an exciting time for newborn screening. Continued funding from (HRSA) allows Genetic Alliance to serve as one of the premier leaders in newborn screening. As a parent and healthcare professional I look forward to working with the Newborn Screening

Clearinghouse as it continues its mission to serve, educate, and disseminate culturally sensitive educational information to parents, healthcare professionals, policy makers and stakeholders.”

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**About Baby's First Test**

*Baby's First Test is the nation's educational resource center for newborn screening. It informs and empowers families and healthcare providers throughout the newborn screening experience. By increasing awareness, Baby's First Test offers millions of newborns and their families a chance at a healthy start. The Newborn Screening Clearinghouse award is supported by the Genetics Services Branch of the Maternal and Child Health Bureau within the Health Resources and Services Administration (HRSA), Cooperative Agreement # U36MC16509. To learn more visit [www.BabysFirstTest.org](http://www.BabysFirstTest.org)*

**About Genetic Alliance**

*Founded in 1986, Genetic Alliance is a nonprofit health advocacy organization that engages individuals, families, and communities to transform health. We bring together diverse stakeholders to create novel partnerships. We promote individualized decision making through increased access to information. We integrate individual, family, and community perspectives to improve health systems and services. To learn more visit [www.GeneticAlliance.org](http://www.GeneticAlliance.org)*

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