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New Resource BabysFirstTest.org Informs Parents and Public about Newborn Screening
Genetic Alliance Launches Vital Newborn Screening Resource

WASHINGTON, DC – September 7, 2011 – Baby’s First Test (www.BabysFirstTest.org) will increase awareness and knowledge of newborn screening and better inform the decision-making process of newborn screening stakeholders, including new parents and healthcare providers across the country. Genetic Alliance (<http://www.geneticalliance.org>) launched this new resource today.

Newborn screening has been available for nearly four decades. However, many parents are unaware of the specific conditions for which babies receive screening in their state, how screening takes place and who to contact for more information. Baby’s First Test will serve as a comprehensive guide for many aspects of newborn screening, including conditions covered and what to do in case of a screen positive test result. Sharon Terry, president and CEO of Genetic Alliance notes, “this site aims to support families by promoting earlier education about newborn screening. It will also provide a resource for healthcare providers to educate parents about what to expect after their baby is born.”

In 2008, the U.S. Congress passed the [Newborn Screening Saves Lives Act](#) to expand support, research, and education opportunities for newborn screening. As a result of this legislation, the Genetic Services Branch of the Maternal and Child Health Bureau, HRSA, HHS [awarded a cooperative agreement](#) to Genetic Alliance and partners to establish an online newborn screening information resource center specifically for parents and the public. The goal is to connect parents and healthcare providers with resources and information relevant to the more than four million newborns screened annually. Since receiving the award, Genetic Alliance and partners mapped out a vision of the site based on this legislation. The process included engagement with state and regional newborn screening programs, input from prenatal care providers, and feedback from consumer advocacy groups. “This launch is a fabulous culmination of a terrific community process, however it is just the beginning for Baby’s First Test. We are excited to continue our collaborative relationships and to build on the foundation of this site,” says Natasha Bonhomme, project director for BabysFirstTest.org

This project has received considerable feedback from the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). R. Rodney Howell, M.D., chairman of the SACHDNC notes, “It is vital that parents and the public know the great benefits of newborn screening. Public dialogue about caring for the children of this nation is essential. BabysFirstTest.org, through its partnerships and social media efforts, provides families with immediate and credible resources and provides critical just-in-time information.”

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About Genetic Alliance

Genetic Alliance improves health through the authentic engagement of communities and

individuals. In this, our 25th year, we celebrate innovation on our journey toward novel partnerships, connected consumers, and smart services. For more information about Genetic Alliance, visit <http://www.geneticalliance.org>.