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Genetic Alliance Applauds Supreme Court Decision on Affordable Care Act
Requires Insurance Companies to Cover Newborn Screening

Washington, DC – June 28, 2012 – Today, the Supreme Court upheld the Patient Protection and Affordable Care Act, which contains several provisions pertaining to newborn screening. “For those of us impacted by genetic diseases, this is a triumph. Alleviating the burden of disease on families in the United States must be a priority and we are grateful the Supreme Court understands this,” said Sharon F. Terry President and CEO of Genetic Alliance.

Based on [Section 2713 \(a\)](#) of the Act, the initial screening for all conditions listed in the Recommended Uniform Screening Panel (RUSP) as approved by the Secretary of the Department of Health and Human Services must be covered. Natasha Bonhomme, Director of Baby’s First Test comments, “This is great news for babies born in the US. We look forward to the continued work needed to ensure that children will have access to full diagnostic and follow-up care.”

Most notably, this includes screening for [critical congenital heart disease](#) and [severe combined immunodeficiency](#), the two conditions most recently added to the RUSP (September 2011 and May 2010 respectively). Insurance companies have one year from when a condition is added to the RUSP to comply with the mandate to cover screening for that condition. There are currently no states screening for every condition on the RUSP, but several are screening for all but one condition. To see what your state screens for, visit [Baby’s First Test](#). For more information on which preventative services are covered by the Affordable Care Act, go to [Healthcare.gov](#).

Christine Brown, Executive Director of the National PKU Alliance notes, “We are pleased with the Supreme Court’s Decision on the Affordable Care Act, since the Act gives many protections needed for those living with [genetic](#) health conditions. While people with PKU and other chronic conditions can no longer be denied health insurance coverage, as the bill is implemented we hope policymakers will pay attention to those living with rare conditions and the impact of the health benefit exchanges.”

For more information about how policies impact newborn screening, visit [www.BabysFirstTest.org](#).

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About Baby's First Test and Genetic Alliance

Baby's First Test, the nation's newborn screening information center, is dedicated to educating parents, health professionals, and the public about the newborn screening system. Baby's First Test provides information and resources about screening at the local, state, and national levels. This initiative is funded through a cooperative agreement from the Genetic Services Branch of the [Maternal and Child Health Bureau](#) of the [Health Resources and Services Administration](#) to [Genetic Alliance](#), a 25-year old non-profit organization that seeks to improve health

through the authentic engagement of communities and individuals. For more information, visit BabysFirstTest.org and GeneticAlliance.org