



Policy Statement

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.

Under the law, parents may request newborn screening tests for conditions not typically screened for by their state—fully covered by insurance—to ensure that their babies are screened for all conditions on the Recommended Uniform Screening Panel (RUSP). Section 2713 (a) of the Act states, "A group health plan and a health insurance issuer offering group or individual health insurance coverage shall, at a minimum provide coverage for and shall not impose any cost sharing requirements for... (3) with respect to infants, children, and adolescents, evidence-informed preventive care and screenings provided for in the comprehensive guidelines supported by the Health Resources and Services Administration." This includes the entirety of the RUSP approved by the Secretary of the Department of Health and Human Services. Natasha Bonhomme, Director of Baby's First Test comments, "We are happy that parents now have a way to ensure that their children have access to screening for all of the RUSP conditions. We look forward to the continued work to ensure that children 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.