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Health and Human Services Secretary Adopts New Recommendation on Newborn  
Screening  
*Recommended Uniform Screening Panel now to include Critical Congenital Heart Disease*

WASHINGTON, DC – September 22, 2011 – Health and Human Services Secretary Kathleen Sebelius adopted the recommendation of the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) that Critical Congenital Heart Disease (CCHD) be included on the Recommended Uniform Screening Panel (RUSP). RUSP is the national recommendation informing states of the congenital conditions that should be included in each state newborn screening program. The SACHDNC put this recommendation forward last year, after following the robust evidence review process they have pioneered. After receiving additional review from the Interagency Coordinating Committee on Screening in Newborns and Children, Secretary Sebelius determined that intervention for this condition during the newborn period is critical to saving lives.

CCHD is a group of heart-related conditions present from birth that cause nearly 3% of infant mortality during the first year of life. Newborn screening for these serious, though often treatable, conditions will include the addition of pulse oximetry screening during the newborn period. Early detection of CCHD, which affects 7 to 9 out of every 1000 live births, allows for critical intervention preventing brain damage, and infant death. This point-of-care screening joins the previously approved blood spot and hearing components of newborn screening.

Genetic Alliance commends Secretary Sebelius’ work and plans to include CCHD in their ongoing newborn screening outreach efforts, through their newborn screening resource Baby’s First Test ([www.babysfirsttest.org](http://www.babysfirsttest.org)).

The process of adding a new condition to the RUSP is a well thought out, rigorous and real, process. Balancing the need for evidence with the urgent needs of the nation’s newborns is critical. We applaud the Secretary’s decision, and look forward to the interagency implementation plan of action, said Natasha Bonhomme, newborn screening director for Genetic Alliance.

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***About Genetic Alliance***

*Genetic Alliance improves health through the authentic engagement of communities and individuals. In this, our 25<sup>th</sup> 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>.*