HHS Adopts Recommendation to Screen Newborns for Heart Defects

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Washington DC (RPRN) 09/22/11 — Newborn Coalition Applauds Action that Will Save Lives

The Newborn Coalition applauds an announcement from United Stated Secretary of Health and Human Services Kathleen Sebelius today that formally adopts the recommendation to add Congenital Cyanotic Heart Disease (CCHD) to the Recommended Uniform Screening Panel.

The announcement addressed the public health importance of early detection of heart defects, and comes almost a full year after the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) voted to recommend all newborns be screened for CCHD.

Heart defects are among the most common birth defects and are the leading cause of birth defect-related deaths. Congenital heart defects occur in 1 in 100, or one percent of live births. Approximately 25 percent of those are classified as critical CHD, requiring intervention in the first weeks or months of life. 4,000 U.S. infants die each year from heart disease. Diagnosing heart problems in newborns is often difficult with clinical examination alone – and detecting CCHD after discharge from the nursery is associated with significantly higher rates of heart-related morbidity and even death. The Secretary's statement recognizes the use of pulse oximetry as a screening tool is a simple, non-invasive, low-cost method to help detect hidden heart

problems in newborns.

“This is a historic day for babies and families. We commend the Secretary and her advisory committee, along with countless advocates, medical professionals and public health leaders for recognizing the vital impact of universal screening for critical heart defects. Simply put, fewer babies will be sent home from the hospital undiagnosed – and lives will be saved,” said Jim Bialick, Executive Director of the Newborn Coalition.

The Secretary’s action is expected to encourage states, health care facilities and clinicians to provide this screening and continue to improve the knowledge base and implementation tactics. It also directs the National Institutes of Health (NIH) to fund research activities, and the Centers for Disease Control (CDC) to fund monitoring activities and HRSA to guide the development of emerging screening standards and educational tools.

“The only thing worse than having a newborn diagnosed with heart disease is having a newborn go undiagnosed with heart disease,” said Annamarie Saarinen, board chair of the Newborn Coalition, and mother of 2-year-old Eve, CCHD survivor. “We were privileged to participate in the federal working group convened by HRSA – along with many skilled and passionate medical professionals, pediatric health organizations, public health leaders, and advocates. We believe much of the early work laid the foundation for states to more fluidly adopt this screening.”

The federal expert working group report has been published online in *Pediatrics* can be viewed here: Newborn Screening for Heart Defects Using Pulse Oximetry Recommended. The report has already been leveraged by states such as New Jersey, which recently became the first state in the country to protect the health of newborns from potentially life threatening heart defects by requiring universal pulse oximetry screening. Several other states have legislation pending or have

implemented pilot programs to screen newborns for heart defects as a standard of care.

The full letter from Secretary Sebelius can be viewed on the SACHDNC website:

http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/index.html

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More about the Newborn Coalition

The Newborn Coalition (www.newborncoalition.org) serves as an unrelenting advocate for infants and families. The coalition leverages health IT and technology innovation to improve outcomes and reduce disparities for the newest, most vulnerable citizens. Co-founded by the mother of a baby diagnosed at 48 hours old with congenital heart disease, the Coalition has a national imprint that supports increased understanding of newborn health issues and risk factors while helping improve access to quality care and resources through vital research and pilot projects.

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