



March 22, 2016

Dear Members of the Committee on Health Care:

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. As part of that mission, we support newborn screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment.

Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. "Critical" congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days, or months of life. Babies with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth. In the United States, about 4,800 babies are born each year with CCHD according to the Centers for Disease Control and Prevention, and an estimated 280 infants are discharged annually from nurseries with undetected CCHD.

CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital, birthing center, or by birth attendant. Pulse oximetry is a bedside test that determines the percent of oxygen saturation of hemoglobin in a baby's blood through a sensor that is usually attached to the baby's finger or foot. If low levels of oxygen saturation in the blood are detected, then further testing can be performed to diagnose any abnormalities in the heart structure or blood flow through the heart. We would suggest that the language in the bill be changed from CHD to CCHD to reflect the severity of the defects to be identified. There are 7 types of CCHD that are the leading cause of death in infants.

Because the screening technology may change from pulse oximetry in the future, the March of Dimes believes it is important to amend H639 to allow for the screening to continue without necessitating changes in the law, and, therefore, without putting newborns at risk. We recommend that the legislative language in H.639 be amended to provide for screening of newborns for critical congenital heart disease through the use of a pulse oximetry test or other means as determined by the Vermont Department of Health. We are aware that currently Vermont hospitals do screen for CCHD and the compliance with this voluntary screening is excellent. We would like to see CCHD screening required by statute in Vermont. The long term sustainability of a voluntary implementation had not been evaluated. The Association of State and Territorial Health Officials has noted that in states with voluntary implementation two of the barriers that have been identified are clear follow up protocols for positive test results, and how often the screening results are reported to public health agencies. The March of Dimes would like to see perhaps a rulemaking change to reflect a working agreement with hospitals to ensure standardized best practices to provide echocardiography and follow up care for infants with a positive result.

Thank you for the opportunity to provide testimony on this important bill. We ask that you support H.639 but also amend the language in the bill to also include testing by home birth attendants. It is important that babies born at home have access to this important screening.

Sincerely,

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