

August 30, 2013

Dear

RE: Critical Congenital Heart Disease Screening Update

On January 1, 2013, Connecticut Public Act No. 12-13: *An Act Concerning Critical Congenital Heart Disease Screening for Newborn Infants* (see below) went into effect. This law requires that hospitals screen for critical congenital heart disease (CCHD) as soon after birth as is medically appropriate. According to the Centers for Disease Control and Prevention (CDC), about 7,200 (or 18 per 10,000) babies born every year in the United States have CCHD. The term CCHD refers to a group of serious heart defects that are present from birth. These abnormalities result from problems with the formation of one or more parts of the heart during the early stages of embryonic development, which prevents the heart from pumping blood effectively or reduces the amount of oxygen in the blood. As a result, organs and tissues throughout the body do not receive enough oxygen, which can lead to organ damage and life-threatening complications.

At this time, there is no requirement that hospitals report screening results to the Department of Public Health (DPH). The DPH does not collect data on any of these screenings or perform follow-up on positive screens: all of this is done at individual hospitals. In addition, the legislation allows hospitals discretion over the type of testing to be used when screening for CCHD, ensuring flexibility in responding to changes in best practices and technology. The DPH will, however, monitor whether CCHD screenings have occurred. Results of screenings must be in the patient's medical record in the event that DPH investigates a complaint regarding the testing, or lack thereof, or if an infant is selected for the sample of patients reviewed during routine onsite visits.

The DPH has created a website dedicated to CCHD, which can be accessed here: <http://www.ct.gov/dph/>. The Centers for Disease Control and Prevention (CDC) provides background, screening algorithm examples, patient education materials and other resources related to CCHD: <http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html>. A sample CCHD screening algorithm from the CDC can be accessed here: <http://www.cdc.gov/ncbddd/pediatricgenetics/pulse.html>.

Thank you for your commitment to protect the lives of infants through comprehensive newborn screening.

Please contact us if you have questions.

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Senate Bill No. 56

Public Act No. 12-13

AN ACT CONCERNING CRITICAL CONGENITAL HEART DISEASE SCREENING FOR NEWBORN INFANTS.

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. Subsection (b) of section 19a-55 of the 2012 supplement to the general statutes is repealed and the following is substituted in lieu thereof (*Effective October 1, 2012*):

(b) In addition to the testing requirements prescribed in subsection (a) of this section, the administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care (1) a screening test for cystic fibrosis, [and] (2) a screening test for severe combined immunodeficiency disease, and (3) on and after January 1, 2013, a screening test for critical congenital heart disease. Such screening tests shall be administered as soon after birth as is medically appropriate.

Approved May 8, 2012