



Senate Bill No. 465

Public Act No. 13-242

AN ACT CONCERNING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY.

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

Section 1. Section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (*Effective October 1, 2013*):

(a) 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 an HIV-related test, as defined in section 19a-581, a test for phenylketonuria and other metabolic diseases, hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia and such other tests for inborn errors of metabolism as shall be prescribed by the Department of Public Health. The tests shall be administered as soon after birth as is medically appropriate. If the mother has had an HIV-related test pursuant to section 19a-90 or 19a-593, the person responsible for testing under this section may omit an HIV-related test. The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover

Senate Bill No. 465

all expenses of the comprehensive screening program including testing, tracking and treatment. The fees to be charged pursuant to subdivision (3) of this subsection shall be set at a minimum of fifty-six dollars. The Commissioner of Public Health shall publish a list of all the abnormal conditions for which the department screens newborns under the newborn screening program, which shall include screening for amino acid disorders, organic acid disorders and fatty acid oxidation disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-CoA dehydrogenase (MCAD).

(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, (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.

(c) On and after the occurrence of the following: (1) The development and validation of a reliable methodology for screening newborns for adrenoleukodystrophy using dried blood spots and quality assurance testing methodology for such test or the approval of a test for adrenoleukodystrophy using dried blood spots by the federal Food and Drug Administration; and (2) the availability of any necessary reagents for such test, 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 a test for adrenoleukodystrophy.

[(c)] (d) The provisions of this section shall not apply to any infant whose parents object to the test or treatment as being in conflict with their religious tenets and practice. The commissioner shall adopt

Senate Bill No. 465

regulations, in accordance with the provisions of chapter 54, to implement the provisions of this section.

Approved July 2, 2013