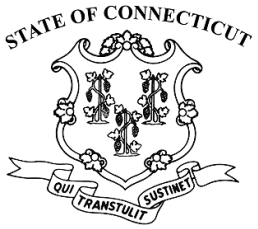

House Bill No. 7282

Public Act No. 19-176

AN ACT CONCERNING NEWBORN SCREENING FOR SPINAL MUSCULAR ATROPHY.

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 Section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (*Effective October 1, 2019*):

(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, severe combined immunodeficiency disease, adrenoleukodystrophy 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 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 ninety-eight 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 (1) every such infant in its care a screening test for (A) cystic fibrosis, **[**and**]** (B) critical congenital heart disease, and (C) on and after January 1, 2020, spinal muscular atrophy, and (2) any newborn infant who fails a newborn hearing screening, as described in section 19a-59, a screening test for cytomegalovirus, provided such screening test shall be administered within available appropriations. **[**on and after January 1, 2016. On and after January 1, 2018, the**]** The administrative officer or other person in charge of each institution caring for newborn infants who performs the testing for critical congenital heart disease shall enter the results of such test into the newborn screening system pursuant to section 19a-53. Such screening tests shall be administered as soon after birth as is medically appropriate.

(c) The administrative officer or other person in charge of each institution caring for newborn infants shall report any case of cytomegalovirus that is confirmed as a result of a screening test administered pursuant to subdivision (2) of subsection (b) of this

section to the Department of Public Health in a form and manner prescribed by the Commissioner of Public Health.

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