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 Section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (Effective October 1, 2019):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

This act shall take effect as follows and shall amend the following sections:

| Section 1 | October 1, 2019 | 19a-55 |

**PH Joint Favorable**