

Substitute Bill No. 6821

January Session, 2023



AN ACT CONCERNING CYTOMEGALOVIRUS.

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 Section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (*Effective October 1, 2023*):
- 3 (a) There is established a newborn screening program. The 4 Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening 5 6 program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to 8 be charged to institutions to cover all expenses of the comprehensive 9 screening program including testing, tracking and treatment, subject to 10 the approval of the Secretary of the Office of Policy and Management. 11 The fees to be charged pursuant to subdivision (3) of this subsection 12 shall be set at a minimum of ninety-eight dollars.
 - (b) The administrative officer or other person in charge of each institution caring for newborn infants, a nurse-midwife licensed pursuant to chapter 377 or a midwife shall cause to have administered to every such newborn infant in his or her care a blood spot specimen and an HIV-related test, as defined in section 19a-581, except that the person responsible for testing may omit such test if the mother has had

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an HIV-related test pursuant to section 19a-90 or 19a-593. The blood spot specimen shall be collected not earlier than twenty-four hours after the birth of the newborn infant and not later than forty-eight hours after the birth of such infant, unless the institution caring for newborn infants, nurse-midwife licensed pursuant to chapter 377 or midwife determines that a situation exists to warrant an early collection of the specimen or if collection of the specimen is medically contraindicated. Situations that warrant early collection of the specimen shall include, but not be limited to, the imminent transfusion of blood products, dialysis, early discharge of the newborn infant from the institution, transfer of the newborn infant to another institution or imminent death. If the newborn infant dies before a blood spot specimen can be obtained, the specimen shall be collected as soon as practicable after death. The institution licensed to care for newborn infants, nurse-midwife or midwife shall notify the Department of Public Health when a specimen is not collected within forty-eight hours after the birth of such infant due to: (1) The infant's medical fragility, (2) refusal by the parents when newborn infant screening is in conflict with their religious tenets and practice, (3) the newborn infant receiving comfort measures only, or (4) any other reason. Such notification shall be documented in the department's newborn screening system pursuant to section 19a-53 by the institution caring for newborn infants, nurse-midwife or midwife or sent in writing to the department not later than seventy-two hours after the birth of the newborn infant. The institution caring for newborn infants, nursemidwife or midwife shall send the blood spot specimen to the state public health laboratory not later than twenty-four hours after the time of collection. The department may request an additional blood spot specimen if: (A) There was an early collection of the specimen, (B) the specimen was collected following a transfusion of blood products, (C) the specimen is unsatisfactory for testing, or (D) the department determines that there is an abnormal result. The state public health laboratory shall make and maintain a record of the date and time of its receipt of each blood spot specimen and make such record available for inspection by the institution caring for newborn infants, nurse-

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midwife or midwife that sent the blood spot specimen not later than forty-eight hours after such institution, nurse-midwife or midwife submits a request to inspect such record.

- (c) 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, but need not be limited to, testing for amino acid disorders, including phenylketonuria, organic acid disorders, fatty acid oxidation disorders, including, but not limited to, long-chain 3-hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-CoA dehydrogenase (MCAD), hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase congenital adrenal hyperplasia, severe immunodeficiency disease, adrenoleukodystrophy, spinal muscular atrophy and any other disorder included on the recommended uniform screening panel pursuant to 42 USC 300b-10, as amended from time to time, and as prescribed by the Commissioner of Public Health.
- (d) In addition to the testing requirements prescribed in subsection (b) 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)] (1) cystic fibrosis, [and (B)] (2) critical congenital heart disease, [(2) any newborn infant who fails a newborn hearing screening, as described in section 19a-59, a screening test for] and (3) cytomegalovirus. Such screening tests shall be administered as soon after birth as is medically appropriate.
 - (e) (1) The clinical laboratory that completes the testing for cystic fibrosis [,] shall report the number of newborn infants screened and the results of such testing, not less than annually, to the Department of Public Health into the newborn screening system pursuant to section 19a-53. The administrative officer or other person in charge of each institution caring for newborn infants who performs the testing for

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- critical congenital heart disease shall enter the results of such test into the newborn screening system pursuant to section 19a-53.
- (2) The administrative officer or other person in charge of each institution caring for newborn infants shall enter any case of cytomegalovirus that is confirmed as a result of a screening test administered pursuant to subdivision [(2)] (3) of subsection (d) of this section to the Department of Public Health into the newborn screening system pursuant to section 19a-53. The provisions of this subsection shall apply regardless of the patient's insurance status or source of payment, including self-pay status.
- (f) 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.
- Sec. 2. (Effective from passage) Not later than January 1, 2024, the Department of Public Health shall disseminate educational materials regarding the symptoms, diagnosis and treatment of cytomegalovirus to (1) each gynecologist, obstetrician and pediatrician in the state for provision by such health care providers to their pregnant and postpartum patients, and (2) the Office of Early Childhood to disseminate to child care centers, group child care homes and family child care homes for provision by such centers and homes to the parent or guardian of each newborn receiving care from the center or home.

This act sh sections:	all take effect as follows	s and shall amend the following
Section 1	October 1, 2023	19a-55
Sec. 2	from passage	New section

Statement of Legislative Commissioners:

In Section 1(e)(2), "subdivision (2)" was changed to "subdivision [(2)] (3)" for accuracy.

PH Joint Favorable Subst.