



General Assembly

Amendment

January Session, 2023

LCO No. 8091



Offered by:

REP. MCCARTHY VAHEY, 133rd Dist.

REP. PARKER, 101st Dist.

To: Subst. House Bill No. **6821**

File No. 171

Cal. No. 136

"AN ACT CONCERNING CYTOMEGALOVIRUS."

1 Strike everything after the enacting clause and substitute the
2 following in lieu thereof:

3 "Section 1. Section 19a-55 of the general statutes is repealed and the
4 following is substituted in lieu thereof (*Effective from passage*):

5 (a) There is established a newborn screening program. The
6 Commissioner of Public Health shall (1) administer the newborn
7 screening program, (2) direct persons identified through the screening
8 program to appropriate specialty centers for treatments, consistent with
9 any applicable confidentiality requirements, and (3) set the fees to be
10 charged to institutions to cover all expenses of the comprehensive
11 screening program including testing, tracking and treatment, subject to
12 the approval of the Secretary of the Office of Policy and Management.
13 The fees to be charged pursuant to subdivision (3) of this subsection
14 shall be set at a minimum of ninety-eight dollars.

15 (b) The administrative officer or other person in charge of each
16 institution caring for newborn infants, a nurse-midwife licensed
17 pursuant to chapter 377 or a midwife shall cause to have administered
18 to every such newborn infant in his or her care a blood spot specimen
19 and an HIV-related test, as defined in section 19a-581, except that the
20 person responsible for testing may omit such test if the mother has had
21 an HIV-related test pursuant to section 19a-90 or 19a-593. The blood spot
22 specimen shall be collected not earlier than twenty-four hours after the
23 birth of the newborn infant and not later than forty-eight hours after the
24 birth of such infant, unless the institution caring for newborn infants,
25 nurse-midwife licensed pursuant to chapter 377 or midwife determines
26 that a situation exists to warrant an early collection of the specimen or if
27 collection of the specimen is medically contraindicated. Situations that
28 warrant early collection of the specimen shall include, but not be limited
29 to, the imminent transfusion of blood products, dialysis, early discharge
30 of the newborn infant from the institution, transfer of the newborn
31 infant to another institution or imminent death. If the newborn infant
32 dies before a blood spot specimen can be obtained, the specimen shall
33 be collected as soon as practicable after death. The institution licensed
34 to care for newborn infants, nurse-midwife or midwife shall notify the
35 Department of Public Health when a specimen is not collected within
36 forty-eight hours after the birth of such infant due to: (1) The infant's
37 medical fragility, (2) refusal by the parents when newborn infant
38 screening is in conflict with their religious tenets and practice, (3) the
39 newborn infant receiving comfort measures only, or (4) any other
40 reason. Such notification shall be documented in the department's
41 newborn screening system pursuant to section 19a-53 by the institution
42 caring for newborn infants, nurse-midwife or midwife or sent in writing
43 to the department not later than seventy-two hours after the birth of the
44 newborn infant. The institution caring for newborn infants, nurse-
45 midwife or midwife shall send the blood spot specimen to the state
46 public health laboratory not later than twenty-four hours after the time
47 of collection. The department may request an additional blood spot
48 specimen if: (A) There was an early collection of the specimen, (B) the
49 specimen was collected following a transfusion of blood products, (C)

50 the specimen is unsatisfactory for testing, or (D) the department
51 determines that there is an abnormal result. The state public health
52 laboratory shall make and maintain a record of the date and time of its
53 receipt of each blood spot specimen and make such record available for
54 inspection by the institution caring for newborn infants, nurse-midwife
55 or midwife that sent the blood spot specimen not later than forty-eight
56 hours after such institution, nurse-midwife or midwife submits a
57 request to inspect such record.

58 (c) The Commissioner of Public Health shall publish a list of all the
59 abnormal conditions for which the department screens newborns under
60 the newborn screening program, which shall include, but need not be
61 limited to, testing for (1) amino acid disorders, including
62 phenylketonuria, organic acid disorders, fatty acid oxidation disorders,
63 including, but not limited to, long-chain 3-hydroxyacyl CoA
64 dehydrogenase (L-CHAD) and medium-chain acyl-CoA
65 dehydrogenase (MCAD), hypothyroidism, galactosemia, sickle cell
66 disease, maple syrup urine disease, homocystinuria, biotinidase
67 deficiency, congenital adrenal hyperplasia, severe combined
68 immunodeficiency disease, adrenoleukodystrophy, spinal muscular
69 atrophy and any other disorder included on the recommended uniform
70 screening panel pursuant to 42 USC 300b-10, as amended from time to
71 time, and as prescribed by the Commissioner of Public Health, and (2)
72 on and after July 1, 2025, cytomegalovirus.

73 (d) In addition to the testing requirements prescribed in subsection
74 (b) of this section, the administrative officer or other person in charge of
75 each institution caring for newborn infants shall cause to have
76 administered to ~~[(1)]~~ every such infant in its care a screening test for
77 ~~[(A)]~~ (1) cystic fibrosis, and ~~[(B)]~~ (2) critical congenital heart disease. ~~[,~~
78 (2) any newborn infant who fails a newborn hearing screening, as
79 described in section 19a-59, a screening test for cytomegalovirus.] Such
80 screening tests shall be administered as soon after birth as is medically
81 appropriate.

82 (e) ~~[(1)]~~ The clinical laboratory that completes the testing for cystic

83 fibrosis [] shall report the number of newborn infants screened and the
84 results of such testing, not less than annually, to the Department of
85 Public Health into the newborn screening system pursuant to section
86 19a-53. The administrative officer or other person in charge of each
87 institution caring for newborn infants who performs the testing for
88 critical congenital heart disease shall enter the results of such test into
89 the newborn screening system pursuant to section 19a-53.

90 [(2) The administrative officer or other person in charge of each
91 institution caring for newborn infants shall enter any case of
92 cytomegalovirus that is confirmed as a result of a screening test
93 administered pursuant to subdivision (2) of subsection (d) of this section
94 to the Department of Public Health into the newborn screening system
95 pursuant to section 19a-53. The provisions of this subsection shall apply
96 regardless of the patient's insurance status or source of payment,
97 including self-pay status.]

98 (f) The provisions of this section shall not apply to any infant whose
99 parents object to the test or treatment as being in conflict with their
100 religious tenets and practice. The commissioner shall adopt regulations,
101 in accordance with the provisions of chapter 54, to implement the
102 provisions of this section.

103 Sec. 2. (*Effective from passage*) (a) The Commissioner of Public Health
104 shall convene a working group to study issues concerning
105 cytomegalovirus, including, but not limited to, screening for
106 cytomegalovirus by other states, treatment for newborns with positive
107 asymptomatic screening results, best practices for universal screening,
108 planning for implementation of universal screening and education for
109 health care providers and vulnerable populations. The commissioner, or
110 the commissioner's designee, shall serve as chairperson of the working
111 group.

112 (b) Not later than January 1, 2025, the Commissioner of Public Health
113 shall report, in accordance with the provisions of section 11-4a of the
114 general statutes, to the joint standing committee of the General

115 Assembly having cognizance of matters relating to public health
116 regarding the findings of the working group."

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>from passage</i>	19a-55
Sec. 2	<i>from passage</i>	New section