



General Assembly

Amendment

January Session, 2013

LCO No. 7469

SB0046507469SD0

Offered by:

SEN. GERRATANA, 6th Dist.
REP. JOHNSON, 49th Dist.
SEN. WELCH, 31st Dist.
REP. SRINIVASAN, 31st Dist.
SEN. FASANO, 34th Dist.
REP. WIDLITZ, 98th Dist.

REP. SAYERS, 60th Dist.
REP. REED, 102nd Dist.
SEN. MEYER, 12th Dist.
REP. KLARIDES, 114th Dist.
REP. CANDELORA, 86th Dist.

To: Senate Bill No. 465

File No. 107

Cal. No. 152

"AN ACT REQUIRING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY."

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 Section 19a-55 of the general statutes is repealed and the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 October 1, 2013*):

5 (a) The administrative officer or other person in charge of each
6 institution caring for newborn infants shall cause to have administered
7 to every such infant in its care an HIV-related test, as defined in section
8 19a-581, a test for phenylketonuria and other metabolic diseases,
9 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine
10 disease, homocystinuria, biotinidase deficiency, congenital adrenal
11 hyperplasia and such other tests for inborn errors of metabolism as

12 shall be prescribed by the Department of Public Health. The tests shall
13 be administered as soon after birth as is medically appropriate. If the
14 mother has had an HIV-related test pursuant to section 19a-90 or 19a-
15 593, the person responsible for testing under this section may omit an
16 HIV-related test. The Commissioner of Public Health shall (1)
17 administer the newborn screening program, (2) direct persons
18 identified through the screening program to appropriate specialty
19 centers for treatments, consistent with any applicable confidentiality
20 requirements, and (3) set the fees to be charged to institutions to cover
21 all expenses of the comprehensive screening program including
22 testing, tracking and treatment. The fees to be charged pursuant to
23 subdivision (3) of this subsection shall be set at a minimum of fifty-six
24 dollars. The Commissioner of Public Health shall publish a list of all
25 the abnormal conditions for which the department screens newborns
26 under the newborn screening program, which shall include screening
27 for amino acid disorders, organic acid disorders and fatty acid
28 oxidation disorders, including, but not limited to, long-chain 3-
29 hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-
30 CoA dehydrogenase (MCAD).

31 (b) In addition to the testing requirements prescribed in subsection
32 (a) of this section, the administrative officer or other person in charge
33 of each institution caring for newborn infants shall cause to have
34 administered to every such infant in its care (1) a screening test for
35 cystic fibrosis, (2) a screening test for severe combined
36 immunodeficiency disease, and (3) on and after January 1, 2013, a
37 screening test for critical congenital heart disease. Such screening tests
38 shall be administered as soon after birth as is medically appropriate.

39 (c) On and after the occurrence of all of the following: (1) The
40 development of a reliable methodology for screening newborns for
41 adrenoleukodystrophy using dried blood spots and quality assurance
42 testing methodology for such test; (2) the registration with the federal
43 Food and Drug Administration of any reagents necessary for such test;
44 (3) the availability from the federal Centers for Disease Control and

45 Prevention of any necessary reagents for such test; and (4) the
 46 acquisition by the Department of Public Health of the equipment
 47 necessary to implement such test, or on and after July 1, 2015,
 48 whichever occurs first, the administrative officer or other person in
 49 charge of each institution caring for newborn infants shall cause to
 50 have administered to every such infant in its care a test for
 51 adrenoleukodystrophy.

52 [(c)] (d) The provisions of this section shall not apply to any infant
 53 whose parents object to the test or treatment as being in conflict with
 54 their religious tenets and practice. The commissioner shall adopt
 55 regulations, in accordance with the provisions of chapter 54, to
 56 implement the provisions of this section."

This act shall take effect as follows and shall amend the following sections:		
Section 1	October 1, 2013	19a-55