

LEGISLATURE OF NEBRASKA
ONE HUNDRED SIXTH LEGISLATURE
SECOND SESSION

LEGISLATIVE BILL 825

Introduced by Hilkemann, 4; DeBoer, 10.

Read first time January 08, 2020

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to infants; to amend section 71-519, Reissue
- 2 Revised Statutes of Nebraska; to require screening of infants for
- 3 spinal muscular atrophy; and to repeal the original section.
- 4 Be it enacted by the people of the State of Nebraska,

1 Section 1. Section 71-519, Reissue Revised Statutes of Nebraska, is
2 amended to read:

3 71-519 (1) All infants born in the State of Nebraska shall be
4 screened for phenylketonuria, congenital primary hypothyroidism,
5 biotinidase deficiency, galactosemia, hemoglobinopathies, medium-chain
6 acyl co-a dehydrogenase (MCAD) deficiency, X-linked adrenoleukodystrophy
7 (X-ALD), mucopolysaccharidoses type 1 (MPS-1), Pompe disease, spinal
8 muscular atrophy, and such other inherited or congenital infant or
9 childhood-onset diseases as the Department of Health and Human Services
10 may from time to time specify. Confirmatory tests shall be performed if a
11 presumptive positive result on the screening test is obtained.

12 (2) The attending physician shall collect or cause to be collected
13 the prescribed blood specimen or specimens and shall submit or cause to
14 be submitted the same to the laboratory designated by the department for
15 the performance of such tests within the period and in the manner
16 prescribed by the department. If a birth is not attended by a physician
17 and the infant does not have a physician, the person registering the
18 birth shall cause such tests to be performed within the period and in the
19 manner prescribed by the department. The laboratory shall within the
20 period and in the manner prescribed by the department perform such tests
21 as are prescribed by the department on the specimen or specimens
22 submitted and report the results of these tests to the physician, if any,
23 the hospital or other birthing facility or other submitter, and the
24 department. The laboratory shall report to the department the results of
25 such tests that are presumptive positive or confirmed positive within the
26 period and in the manner prescribed by the department.

27 (3) The hospital or other birthing facility shall record the
28 collection of specimens for tests for metabolic diseases and the report
29 of the results of such tests or the absence of such report. For purposes
30 of tracking, monitoring, and referral, the hospital or other birthing
31 facility shall provide from its records, upon the department's request,

1 information about the infant's and mother's location and contact
2 information, and care and treatment of the infant.

3 (4)(a) The department shall have authority over the use, retention,
4 and disposal of blood specimens and all related information collected in
5 connection with disease testing conducted under subsection (1) of this
6 section.

7 (b) The department shall adopt and promulgate rules and regulations
8 relating to the retention and disposal of such specimens. The rules and
9 regulations shall: (i) Be consistent with nationally recognized standards
10 for laboratory accreditation and shall comply with all applicable
11 provisions of federal law; (ii) require that the disposal be conducted in
12 the presence of a witness who may be an individual involved in the
13 disposal or any other individual; and (iii) provide for maintenance of a
14 written or electronic record of the disposal, verified by such witness.

15 (c) The department shall adopt and promulgate rules and regulations
16 relating to the use of such specimens and related information. Such use
17 shall only be made for public health purposes and shall comply with all
18 applicable provisions of federal law. The department may charge a
19 reasonable fee for evaluating proposals relating to the use of such
20 specimens for public health research and for preparing and supplying
21 specimens for research proposals approved by the department.

22 (5) The department shall prepare written materials explaining the
23 requirements of this section. The department shall include the following
24 information in the pamphlet:

25 (a) The nature and purpose of the testing program required under
26 this section, including, but not limited to, a brief description of each
27 condition or disorder listed in subsection (1) of this section;

28 (b) The purpose and value of the infant's parent, guardian, or
29 person in loco parentis retaining a blood specimen obtained under
30 subsection (6) of this section in a safe place;

31 (c) The department's procedures for retaining and disposing of blood

1 specimens developed under subsection (4) of this section; and

2 (d) That the blood specimens taken for purposes of conducting the
3 tests required under subsection (1) of this section may be used for
4 research pursuant to subsection (4) of this section.

5 (6) In addition to the requirements of subsection (1) of this
6 section, the attending physician or person registering the birth may
7 offer to draw an additional blood specimen from the infant. If such an
8 offer is made, it shall be made to the infant's parent, guardian, or
9 person in loco parentis at the time the blood specimens are drawn for
10 purposes of subsection (1) of this section. If the infant's parent,
11 guardian, or person in loco parentis accepts the offer of an additional
12 blood specimen, the blood specimen shall be preserved in a manner that
13 does not require special storage conditions or techniques. The attending
14 physician or person making the offer shall explain to the parent,
15 guardian, or person in loco parentis at the time the offer is made that
16 the additional blood specimen can be used for future identification
17 purposes and should be kept in a safe place. The attending physician or
18 person making the offer may charge a fee that is not more than the actual
19 cost of obtaining and preserving the additional blood specimen.

20 (7) The person responsible for causing the tests to be performed
21 under subsection (2) of this section shall inform the parent or legal
22 guardian of the infant of the tests and of the results of the tests and
23 provide, upon any request for further information, at least a copy of the
24 written materials prepared under subsection (5) of this section.

25 (8) Dietary and therapeutic management of the infant with
26 phenylketonuria, primary hypothyroidism, biotinidase deficiency,
27 galactosemia, hemoglobinopathies, MCAD deficiency, X-linked
28 adrenoleukodystrophy (X-ALD), mucopolysaccharidoses type 1 (MPS-1), Pompe
29 disease, spinal muscular atrophy, or such other inherited or congenital
30 infant or childhood-onset diseases as the department may from time to
31 time specify shall be the responsibility of the child's parent, guardian,

1 or custodian with the aid of a physician selected by such person.

2 (9) Except for acts of gross negligence or willful or wanton
3 conduct, any physician, hospital or other birthing facility, laboratory,
4 or other submitter making reports or notifications under sections 71-519
5 to 71-524 shall be immune from criminal or civil liability of any kind or
6 character based on any statements contained in such reports or
7 notifications.

8 Sec. 2. Original section 71-519, Reissue Revised Statutes of
9 Nebraska, is repealed.