

LEGISLATURE OF NEBRASKA
ONE HUNDREDTH LEGISLATURE
SECOND SESSION

LEGISLATIVE BILL 809

Introduced by Synowiecki, 7.

Read first time January 10, 2008

Committee: Health and Human Services

A BILL

1 FOR AN ACT relating to metabolic screening; to amend section
2 71-519, Revised Statutes Supplement, 2007; to provide for
3 an exemption; to harmonize provisions; and to repeal the
4 original section.

5 Be it enacted by the people of the State of Nebraska,

1 Section 1. Section 71-519, Revised Statutes Supplement,
2 2007, is amended to read:

3 71-519 ~~(1)~~ All (1)(a) Except as provided in subdivision
4 (b) of this subsection, all infants born in the State of Nebraska
5 shall be screened for phenylketonuria, primary hypothyroidism,
6 biotinidase deficiency, galactosemia, hemoglobinopathies,
7 medium-chain acyl co-a dehydrogenase (MCAD) deficiency, and
8 such other metabolic diseases as the Department of Health and Human
9 Services may from time to time specify. Confirmatory tests shall be
10 performed if a presumptive positive result on the screening test
11 is obtained.

12 (b) A parent or legal guardian of an infant born in
13 the State of Nebraska shall be granted an exemption from the
14 requirements of subdivision (a) of this subsection on behalf of the
15 infant upon the filing of a written objection with the department
16 based on the sincerely held religious beliefs of the parent or
17 legal guardian, pursuant to rules and regulations adopted and
18 promulgated by the department.

19 (2) Persons responsible for causing the tests to be
20 performed under subsection (3) of this section shall inform the
21 parent or legal guardian of the infant that the parent or legal
22 guardian may refuse to have the tests performed upon filing a
23 written objection pursuant to subdivision (1)(a) of this section.
24 If the parent or legal guardian of an infant objects to testing the
25 infant for heritable and congenital disorders, the objection shall

1 be made in writing on a form signed by the parent or legal guardian
2 and the form shall be made part of the infant's medical record.

3 ~~(2)~~ (3) The attending physician shall collect or cause
4 to be collected the prescribed blood specimen or specimens and
5 shall submit or cause to be submitted the same to the laboratory
6 designated by the department for the performance of such tests
7 within the period and in the manner prescribed by the department.
8 If a birth is not attended by a physician and the infant does
9 not have a physician, the person registering the birth shall
10 cause such tests to be performed within the period and in the
11 manner prescribed by the department. The laboratory shall within
12 the period and in the manner prescribed by the department perform
13 such tests as are prescribed by the department on the specimen
14 or specimens submitted and report the results of these tests to
15 the physician, if any, the hospital or other birthing facility or
16 other submitter, and the department. The laboratory shall report
17 to the department the results of such tests that are presumptive
18 positive or confirmed positive within the period and in the manner
19 prescribed by the department.

20 ~~(3)~~ (4) The hospital or other birthing facility shall
21 record the collection of specimens for tests for metabolic diseases
22 and the report of the results of such tests or the absence of such
23 report. For purposes of tracking, monitoring, and referral, the
24 hospital or other birthing facility shall provide from its records,
25 upon the department's request, information about the infant's and

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

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

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

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

24 ~~(5)~~ (6) The department shall prepare written materials
25 explaining the requirements of this section. The department shall

1 include the following information in the pamphlet:

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

6 (b) The purpose and value of the infant's parent,
7 guardian, or person in loco parentis retaining a blood specimen
8 obtained under subsection ~~(6)~~ (7) of this section in a safe place;

9 (c) The department's procedures for retaining and
10 disposing of blood specimens developed under subsection ~~(4)~~ (5) of
11 this section; and

12 (d) That the blood specimens taken for purposes of
13 conducting the tests required under subsection (1) of this section
14 may be used for research pursuant to subsection ~~(4)~~ (5) of this
15 section.

16 ~~(6)~~ (7) In addition to the requirements of subsection
17 (1) of this section, the attending physician or person registering
18 the birth may offer to draw an additional blood specimen from
19 the infant. If such an offer is made, it shall be made to the
20 infant's parent, guardian, or person in loco parentis at the
21 time the blood specimens are drawn for purposes of subsection (1)
22 of this section. If the infant's parent, guardian, or person in
23 loco parentis accepts the offer of an additional blood specimen,
24 the blood specimen shall be preserved in a manner that does not
25 require special storage conditions or techniques, including, but

1 not limited to, lamination. The attending physician or person
2 making the offer shall explain to the parent, guardian, or person
3 in loco parentis at the time the offer is made that the additional
4 blood specimen can be used for future identification purposes and
5 should be kept in a safe place. The attending physician or person
6 making the offer may charge a fee that is not more than the actual
7 cost of obtaining and preserving the additional blood specimen.

8 ~~(7)~~ (8) The person responsible for causing the tests to
9 be performed under subsection ~~(2)~~ (3) of this section shall inform
10 the parent or legal guardian of the infant of the tests and of
11 the results of the tests and provide, upon any request for further
12 information, at least a copy of the written materials prepared
13 under subsection ~~(5)~~ (6) of this section.

14 ~~(8)~~ (9) Dietary and therapeutic management of the
15 infant with phenylketonuria, primary hypothyroidism, biotinidase
16 deficiency, galactosemia, hemoglobinopathies, MCAD deficiency, or
17 such other metabolic diseases as the department may from time to
18 time specify shall be the responsibility of the child's parent,
19 guardian, or custodian with the aid of a physician selected by such
20 person.

21 ~~(9)~~ (10) Except for acts of gross negligence or willful
22 or wanton conduct, any physician, hospital or other birthing
23 facility, laboratory, or other submitter making reports or
24 notifications under sections 71-519 to 71-524 shall be immune from
25 criminal or civil liability of any kind or character based on any

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1 statements contained in such reports or notifications.

2 Sec. 2. Original section 71-519, Revised Statutes

3 Supplement, 2007, is repealed.