

AMENDMENTS TO LB 797

Introduced by Synowiecki, 7.

1 1. Insert the following new section:

2 Sec. 3. Section 71-519, Revised Statutes Supplement,
3 2007, is amended to read:

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

13 (b) A parent or legal guardian of an infant subject to
14 the requirements of subdivision (a) of this subsection may request
15 and shall be granted an exemption from such requirements on behalf
16 of the infant based on the sincerely held religious beliefs of
17 such parent or legal guardian. Such request shall be made in
18 writing on a form developed by the department and filed with the
19 attending physician or person registering the infant's birth under
20 subsection (2) of this section. Such request shall be reported
21 to the department and shall be made part of the infant's medical
22 record. The department shall make forms available to request and
23 report such exemption. Such forms shall include a warning and

1 relevant information relating to the risks associated with the
2 failure to receive the screening.

3 (2) The attending physician shall collect or cause to
4 be collected the prescribed blood specimen or specimens and shall
5 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) The hospital or other birthing facility shall record
21 the collection of specimens for tests for metabolic diseases and
22 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
26 mother's location and contact information, and care and treatment
27 of the infant.

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

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

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

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

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

1 of this section;

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

5 (c) The department's procedures for retaining and
6 disposing of blood specimens developed under subsection (4) of this
7 section; and

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

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

1 cost of obtaining and preserving the additional blood specimen.

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

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

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

20 2. Renumber the remaining sections and correct internal
21 references accordingly.

22 3. Correct the operative date and repealer sections so
23 that the section added by this amendment becomes operative three
24 calendar months after the adjournment of this legislative session.