LEGISLATURE OF NEBRASKA

ONE HUNDREDTH LEGISLATURE

FIRST SESSION

LEGISLATIVE BILL 250

Introduced By: Synowiecki, 7
Read first time: January 10, 2007
Committee: Health and Human Services

A BILL

FOR AN ACT relating to public health and welfare; to amend sections 71-519 and 71-522, Revised Statutes Cumulative Supplement, 2006; to provide a religious exemption to infant screening requirements; to harmonize provisions; and to repeal the original sections.

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

Section 1. Section 71-519, Revised Statutes Cumulative Supplement, 2006, is amended to read:

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

(b) A parent or guardian of an infant born in the State of Nebraska may request and may be granted an exemption from the provisions of subdivision (a) of this subsection on behalf of the infant upon the filing of a written objection with the department based on the sincerely held religious beliefs of the parent or guardian pursuant to rules and regulations adopted and promulgated by the department. A parent or guardian who files the written objection shall assume all liability for medical costs that may result from, and are directly related to, the decision to exempt the infant from the provisions of subdivision (a) of this subsection.

(c) The State of Nebraska and the department shall assume no liability for medical costs that may result from, and are directly related to, the decision to exempt the infant from the provisions of subdivision (a) of this subsection.

(d) A physician, a registered nurse, a health care provider, a hospital or other birthing facility, a clinical

laboratory, or any other officer or employee of a physician, a hospital or other birthing facility, or a clinical laboratory is not criminally or civilly liable for reporting information in good faith to the department or its designee as described in this section prior to the parent or guardian of the infant filing a written objection pursuant to subdivision (b) of this subsection.

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

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

department's request, information about the infant's and mother's location and contact information, and care and treatment of the infant.

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

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

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

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

(a) The nature and purpose of the testing program required under this section, including, but not limited to, a brief description of each condition or disorder listed in ~~subsection (1)~~ subdivision (1)(a) of this section and the ability of a parent or guardian to file a written objection as provided in subdivision (1)(b) of this section;

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

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

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

(6) In addition to the requirements of subsection (1) of this section, the attending physician or person registering the birth may offer to draw an additional blood specimen from the infant. If such an offer is made, it shall be made to the infant's parent, guardian, or person in loco parentis at the time the blood specimens are drawn for purposes of subsection (1) of this section. If the infant's parent, guardian, or person in loco parentis accepts the offer of an additional blood specimen, the blood specimen shall be preserved in a manner that does not require special storage conditions or techniques, including, but not limited to, lamination. The attending physician or person making the offer shall explain to the parent, guardian, or person in loco parentis at the time the offer is made that the additional blood specimen can be used for future

identification purposes and should be kept in a safe place. The attending physician or person making the offer may charge a fee that is not more than the actual cost of obtaining and preserving the additional blood specimen.

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

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

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

Sec. 2. Section 71-522, Revised Statutes Cumulative Supplement, 2006, is amended to read:

71-522. The Department of Health and Human Services Regulation and Licensure shall establish and maintain a central data registry for the collection and storage of reported data concerning

metabolic diseases. The department shall use reported data to ensure that ~~all~~ infants born in the State of Nebraska are tested for diseases ~~set forth in~~ as provided by section 71-519 or by rule and regulation. The department shall also use reported data to evaluate the quality of the statewide system of newborn screening and develop procedures for quality assurance. Reported data in anonymous or statistical form may be made available by the department for purposes of research.

Sec. 3. Original sections 71-519 and 71-522, Revised Statutes Cumulative Supplement, 2006, are repealed.