

LEGISLATURE OF NEBRASKA  
ONE HUNDRED NINTH LEGISLATURE  
FIRST SESSION

**LEGISLATIVE BILL 310**

Introduced by Hansen, 16.

Read first time January 15, 2025

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to public health and welfare; to amend section
- 2 71-519, Revised Statutes Cumulative Supplement, 2024; to provide an
- 3 exemption from newborn screening as prescribed; 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 Cumulative Supplement,  
2 2024, is 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 (10) Nothing in this section shall be construed to require an infant  
9 to submit to screening as provided in subsection (1) of this section if  
10 the parent or guardian of such infant objects to such screening.

11 **Sec. 2.** Original section 71-519, Revised Statutes Cumulative  
12 Supplement, 2024, is repealed.