

## LEGISLATIVE BILL 385

Approved by the Governor February 20, 1987

Introduced by Health & Human Services Committee, Wesely 26, Chairperson; Morehead, 30; Lynch, 13; Schellpeper, 18; Pappas, 42; Goodrich, 20; Beyer, 3; Conway, 17

AN ACT relating to public health and welfare; to provide for testing for metabolic diseases; to provide fees; to provide powers and duties for the Department of Health; to provide for a registry; to provide for enforcement; to eliminate provisions for screenings as prescribed; and to repeal sections 71-604.01, 71-604.03, and 71-604.04, Reissue Revised Statutes of Nebraska, 1943.

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

Section 1. All infants born in the State of Nebraska shall be screened for phenylketonuria, primary hypothyroidism, biotinidase deficiency, and such other metabolic diseases as the Department of Health may from time to time specify. Confirmatory tests shall be performed in the event that a presumptive positive result on the screening test is obtained.

The attending physician shall collect or cause to be collected the prescribed specimen or specimens and shall submit or cause to be submitted the same to a laboratory for the performance of such tests within the period prescribed by the Department of Health. In the event a birth is not attended by a physician, the person registering the birth shall cause such tests to be performed within the period prescribed by the department. The laboratory shall within the period 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, and the department.

The hospital shall record the collection of specimens for tests for metabolic diseases and the reporting of the results of such tests or the absence of such report. In the event that the specimen was not collected or the report of the results of the tests was not obtained, the hospital shall notify the Department of Health within the period prescribed by the

department.

Dietary and therapeutic management of the infant with phenylketonuria, primary hypothyroidism, biotinidase deficiency, or such other metabolic diseases as the Department of Health 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.

Sec. 2. The Department of Health may, in its discretion, establish a program to provide food supplements to children suffering from the metabolic diseases set forth in section 1 of this act. To defray or help defray the costs of any program which may be established by the department under this section, the department may prescribe and assess a scale of fees for the food supplements. The maximum prescribed fee shall be no more than the actual cost of such supplements. Any fees collected shall be deposited in the state treasury and shall be credited to the Department of Health Cash Fund.

Sec. 3. The Department of Health shall prescribe the tests, the test methods and techniques, and such reports and reporting procedures as are necessary to implement sections 1 to 6 of this act.

The Department of Health shall set fees for metabolic disease tests performed by the department's laboratory. The fees shall be set at the rate necessary to recover the actual costs of providing such tests. Such fees shall be deposited in the state treasury and credited to the Department of Health Cash Fund.

Sec. 4. The Department of Health 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 section 1 of this act or by rule and regulation. Reported data in anonymous or statistical form may be made available by the department for purposes of research.

Sec. 5. (1) The Department of Health shall provide educational and resource services regarding metabolic diseases to persons affected by sections 1 to 6 of this act and to the public generally.

(2) The department may apply for, receive, and administer federal or other funds which are available for the purpose of implementing sections 1 to 6 of this act and may contract for or provide services as may be necessary.

(3) The department shall adopt and promulgate

rules and regulations to implement sections 1 to 6 of this act.

Sec. 6. In addition to any other remedies which may be available by law, a civil proceeding to enforce section 1 of this act may be brought in the district court of the county where the infant is domiciled or found. The attending physician, the hospital, the Attorney General, or the county attorney of the county where the infant is domiciled or found may institute such proceedings as are necessary to enforce such section. It shall be the duty of the Attorney General or the county attorney to whom the Director of Health reports a violation to cause appropriate proceedings to be initiated without delay. A hearing on any action brought pursuant to this section shall be held within seventy-two hours of the filing of such action, and a decision shall be rendered by the court within twenty-four hours of the close of the hearing.

Sec. 7. That sections 71-604.01, 71-604.03, and 71-604.04, Reissue Revised Statutes of Nebraska, 1943, are repealed.