

Introduced by

Human Services Committee

(At the request of the State Department of Health)

1 A BILL for an Act to amend and reenact section 23-01-03.1, subsection 3 of section 25-17-00.1,
2 and sections 25-17-01, 25-17-03, and 25-17-04 of the North Dakota Century Code, relating to
3 newborn disease screening and research regarding metabolic and genetic diseases.

4 **BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

5 **SECTION 1. AMENDMENT.** Section 23-01-03.1 of the North Dakota Century Code is
6 amended and reenacted as follows:

7 **23-01-03.1. Newborn metabolic and genetic disease screening tests.**

8 The health council may authorize the use of newborn metabolic and genetic disease
9 screening tests, as provided for in chapter 25-17, for research purposes. The council shall adopt
10 rules to ensure that the results are used for legitimate research purposes and to ensure that the
11 confidentiality of the newborns and their families is protected.

12 **SECTION 2. AMENDMENT.** Subsection 3 of section 25-17-00.1 of the North Dakota
13 Century Code is amended and reenacted as follows:

14 3. "Metabolic disease" ~~means~~and "genetic disease" mean a disease as designated by
15 rule of the state health council for which early identification and timely intervention will
16 lead to a significant reduction in mortality, morbidity, and associated disabilities.

17 **SECTION 3. AMENDMENT.** Section 25-17-01 of the North Dakota Century Code is
18 amended and reenacted as follows:

19 **25-17-01. Newborn screening education programs and tests.**

20 The state department of health shall:

21 1. Develop and implement a metabolic and genetic disease educational program among
22 physicians, hospital staffs, public health nurses, and the citizens of this state. This
23 educational program must include information about the nature of the diseases and

1 about screening for the early detection of these diseases so that proper measures
2 may be taken to reduce mortality, morbidity, and associated disabilities.

3 2. Provide, on a statewide basis, a newborn screening system and short-term followup
4 services for metabolic and genetic diseases.

5 3. Coordinate with or refer individuals to public and private health care service providers
6 for long-term followup services for metabolic diseases or genetic diseases, or both.

7 **SECTION 4. AMENDMENT.** Section 25-17-03 of the North Dakota Century Code is
8 amended and reenacted as follows:

9 **25-17-03. Treatment for positive diagnosis - Registry of cases.**

10 The state department of health shall:

11 1. Follow up with attending physicians cases with positive tests for metabolic diseases or
12 genetic diseases, or both, in order to determine the exact diagnosis.

13 2. Refer every diagnosed case of a metabolic disease or genetic disease, or both, to a
14 qualified health care provider for necessary treatment ~~of the metabolic disease.~~

15 3. Maintain a registry of cases of metabolic and genetic diseases.

16 4. Provide medical food at no cost to males under age twenty-two and females under
17 age forty-five who are diagnosed with phenylketonuria or maple syrup urine disease,
18 regardless of income. If treatment services under this subsection are provided to an
19 individual by the department, the department may seek reimbursement from any
20 government program that provides coverage to that individual for the treatment
21 services provided by the department.

22 5. Offer for sale at cost medical food to females age forty-five and over and to males age
23 twenty-two and over who are diagnosed with phenylketonuria or maple syrup urine
24 disease, regardless of income. These individuals are responsible for payment to the
25 department for the cost of medical food.

26 6. Provide low-protein modified food products, if medically necessary as determined by a
27 qualified health care provider, to females under age forty-five and males under age
28 twenty-two who are receiving medical assistance and are diagnosed with
29 phenylketonuria or maple syrup urine disease.

30 **SECTION 5. AMENDMENT.** Section 25-17-04 of the North Dakota Century Code is
31 amended and reenacted as follows:

1 **25-17-04. Testing and reporting requirements.**

2 The physician attending a newborn child, or the birth attendant in the case of an
3 out-of-hospital birth, shall provide the parents with written information regarding the nature of
4 the proposed testing and then cause that newborn child to be subjected to testing for metabolic
5 and genetic diseases, in the manner prescribed by the state department of health. A physician
6 attending a patient with a metabolic disease or genetic disease, or both, shall report the case to
7 the state department of health. The testing requirements of this section do not apply if the
8 parents of a newborn child object to the testing ~~on the grounds that testing for metabolic or~~
9 ~~genetic diseases, or both, conflicts with their religious tenets and practices.~~