State of Minnesota
HOUSE OF REPRESENTATIVES

EIGHTY-FIFTH
SESSION

HOUSE FILE NO. 3438

February 25, 2008
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The bill was read for the first time and referred to the Committee on Public Safety and Civil Justice
March 10, 2008
Committee Recommendation and Adoption of Report:
To Pass as Amended and re-referred to the Committee on Health and Human Services

A bill for an act
relating to health; changing provisions for handling genetic information; amending Minnesota Statutes 2006, section 13.386, subdivision 3; Minnesota Statutes 2007 Supplement, section 144.125, subdivision 3.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

Section 1. Minnesota Statutes 2006, section 13.386, subdivision 3, is amended to read:

Subd. 3. **Collection, storage, use, and dissemination of genetic information.** (a) Unless otherwise expressly provided by law, genetic information about an individual:

(1) may be collected by a government entity, as defined in section 13.02, subdivision 7a, or any other person only with the written informed consent of the individual;

(2) may be used only for purposes to which the individual has given written informed consent;

(3) may be stored only for a period of time to which the individual has given written informed consent; and

(4) may be disseminated only:

(i) with the individual's written informed consent; or

(ii) if necessary in order to accomplish purposes described by clause (2). A consent to disseminate genetic information under item (i) must be signed and dated. Unless otherwise provided by law, such a consent is valid for one year or for a lesser period specified in the consent.

(b) Notwithstanding this subdivision, the Department of Health's collection, storage, use, and dissemination of genetic information and blood specimens for testing infants for heritable and congenital disorders are governed by sections 144.125 to 144.128.

Sec. 2. Minnesota Statutes 2007 Supplement, section 144.125, subdivision 3, is amended to read:

Subd. 3. **Objection of parents to test.** (a) Persons with a duty to perform testing under subdivision 1 ~~shall advise~~ must provide parents of infants with a document explaining: (1) that the blood or tissue samples used to perform testing thereunder as well as the results of such testing may be retained by the Department of Health~~,~~; (2) the benefit of retaining the blood or tissue sample~~, and~~; (3) that the following ~~options~~ alternatives are available to them with respect to the testing: (i) to decline to have the tests, ~~or~~ (ii) to elect to have the tests, but to require that all blood samples and records of test results be destroyed within 24 months of the testing, or (iii) to decline to have the test results and samples used for public health studies and research, or both; (4) the data that will be collected as a result of the testing; and (5) the ways in which the samples and data collected will be stored and used.

(b) The document provided under paragraph (a) must inform parents of their right to object under paragraph (a), clause (3). If the parents of an infant object in writing to testing for heritable and congenital disorders or elect to require that blood samples and test results be destroyed, or elect to decline to have the test results used for public health studies and research, the objection or election shall be recorded on a form that is signed by a parent or legal guardian and made part of the infant's medical record. When a parent objects, the Department of Health must follow the requirements of paragraph (a), clause (3), and section 144.128. A written objection exempts an infant from the requirements of this section and section 144.128.

(c) For purposes of this subdivision, "public health studies and research" includes calibrating newborn screening equipment, evaluating existing newborn screening tests to reduce the number of false positive and false negative results, studying the development of new newborn screening tests for heritable and congenital disorders, and other population-based health studies.

Sec. 3. **NEWBORN SCREENING REPORT.**

By January 15, 2009, the Department of Health shall report and make recommendations to the legislature on its current efforts for ensuring and enhancing how parents of newborns are fully informed about the newborn screening program and of their rights and options regarding: (1) testing; (2) storage; (3) public health practices, studies, and research; (4) the ability to opt out of the collection of data and specimens related to the testing; and (5) the ability to seek private testing.