

HOUSE RESEARCH

Bill Summary

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Subject: Treatment of Genetic Information held by the Department of Health

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Overview

In 2006, Minnesota Statutes, § 13.386 was enacted to govern the treatment of genetic information held by government entities. After enactment, there was litigation that challenged whether the statute governed activities conducted by the Minnesota Department of Health (MDH) as part of its newborn screening program, under Minnesota Statutes, §§ 144.125 to 144.128. In 2012, a public health exception was enacted as part of the genetic information law to permit MDH to continue its other activities for approximately one year, while analyzing the interplay between these other activities and the genetic information law. This bill would exempt certain MDH activities from § 13.386 and would establish requirements for the treatment of genetic information held by MDH. This bill does not address the newborn screening program and does not exempt that program from § 13.386.

Section

- 1** **Collection, storage, use, and dissemination of genetic information.** Amends § 13.386, subd. 3. Provides that this section governs the collection, storage, use and dissemination of genetic information for activities under the newborn screening program, but § 144.192 governs treatment of biological specimens and health data for other public health programs.
- 2** **Treatment of biological specimens and health data held by the department of health and health boards.** Adds § 144.192.

Subd. 1. Definitions. Defines the following terms for purposes of this section: biological specimen; health data; health oversight; individual; person; program operations; public health practice; representative of the decedent; and research.

Section

Subd. 2. Collection, use, storage, and dissemination. Permits the commissioner to collect, store, use and disseminate biological specimens and health data, including genetic data, as provided in this section or as permitted elsewhere in law. States that this provision does not supersede or repeal other existing law that applies. Specifies that for purposes of this section, genetic information is limited to biological specimens and health data.

Subd. 3. Biological specimens and health data for program operations, public health practice, and health oversight. (a) Permits the commissioner to collect, store, use and disseminate biological specimens and health data for program operations, public health activities, and health oversight. Provides that unless required in law, consent of an individual is not required for these activities.

(b) Provides the purposes for which biological specimens may be disseminated with the approval of the commissioner.

(c) Permits the commissioner to disseminate to public health labs, under certain circumstances, de-identified biological specimens for purposes of clinical laboratory (CLIA) proficiency testing.

(d) Provides that health data may be disseminated as provided in section 13.3805, subd. 1.

Subd. 4. Research. Permits the commissioner to collect, use, store and disseminate biological specimens and health data to conduct research in a manner consistent with federal law.

Subd. 5. Storage of biological specimens and health data according to storage schedules. Requires the commissioner to store health data was provided in section 138.17. Requires the commissioner to store biological specimens according to a storage schedule to be developed by July 1, 2013. Requires that the storage schedule be posted on the department's website.

Subd. 6. Secure storage of biological specimens. Requires the commissioner to establish security safeguards for the storage of biological specimens and to store specimens according to those safeguards. Requires that when a specimen is disposed of, it must be in such a way as to prevent determining identity.

Subd. 7. Applicability to health boards. Provides that certain provisions of this section apply to boards of health and community health boards organized under chapter 145A. Permits these boards to disseminate health data pursuant to § 13.3805, subd. 1, paragraph (b), clause (2).

3 Early hearing detection and intervention programs. Amends § 144.966, subd. 3. Makes conforming technical change.

4 Construction. Amends § 144.966, subd. 8. Provides that the early hearing detection and intervention program is not a newborn screening activity under Minnesota Statutes, §§

Section

144.125 to 144.128.

5 **Effective date.** Provides that sections 1 to 4 are effective July 1, 2013.