

A bill for an act

relating to genetic information; specifying how genetic information is to be treated; requiring informed consent prior to collecting genetic information and biological specimens; classifying data collection; amending Minnesota Statutes 2008, sections 13.3805, by adding a subdivision; 13.384, subdivision 1, by adding a subdivision; 144.69; 299C.155, subdivisions 1, 3, 4, by adding subdivisions; proposing coding for new law in Minnesota Statutes, chapter 144; repealing Minnesota Statutes 2008, section 13.386; Minnesota Rules, part 4606.3306.

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

Section 1. Minnesota Statutes 2008, section 13.3805, is amended by adding a subdivision to read:

Subd. 1a. **Three-generation pedigree.** "Three-generation pedigree" means a pictorial representation or narrative of family health history given by an individual, including the names of other family members and their relationship to the individual. A three-generation pedigree does not include the results of any tests from the individual's or family member's medical record. A three-generation pedigree is health data about the individual. The individual is the data subject of the pedigree and has access to all of the data in the pedigree. The three-generation pedigree health data under this subdivision is classified as private data on individuals under section 13.02, subdivision 12.

Sec. 2. Minnesota Statutes 2008, section 13.384, subdivision 1, is amended to read:

Subdivision 1. **Definition.** As used in this section:

(a) "Directory information" means name of the patient, date admitted, and general condition.

(b) "Medical data" means data collected because an individual was or is a patient or client of a hospital, nursing home, medical center, clinic, health or nursing agency

operated by a government entity including business and financial records, data provided by private health care facilities, and data provided by or about relatives of the individual.

(c) "Three-generation pedigree" means a pictorial representation or narrative of family health history given by an individual, including the names of other family members and their relationship to the individual. A three-generation pedigree does not include the results of any tests from the individual's or family member's medical record. The three-generation pedigree is classified as private data on individuals under section 13.02, subdivision 12.

Sec. 3. Minnesota Statutes 2008, section 13.384, is amended by adding a subdivision to read:

Subd. 4. **Three-generation pedigree.** A three-generation pedigree is medical data about the individual. The individual is the data subject of the pedigree and has access to all of the data in the pedigree. The three-generation pedigree is classified as private data on individuals under section 13.02, subdivision 12.

Sec. 4. **[144.3346] GENETIC INFORMATION HELD BY GOVERNMENT AND PRIVATE MEDICAL CARE PROVIDERS.**

Subdivision 1. **Definition.** (a) "Genetic information" means information about an identifiable individual derived from the presence, absence, alteration, or mutation of a gene, or the presence or absence of a specific human DNA or RNA marker that is known to be the cause of a disease or disorder, which has been obtained from the analysis of a human biological specimen.

(b) "Genetic information" also means family history and medical information collected from an individual about a particular disease or disorder that is known to have a genetic component that is or might be used to provide medical care to that individual.

Subd. 2. **Data classification.** Genetic information held by a government entity, as defined in section 13.02, subdivision 7a, is private data on individuals. The subject of these private data is the individual from whom the government entity collects the genetic information.

Subd. 3. **Collection and use of genetic information and human biological specimens.** (a) Unless otherwise exempted by law, government entities, as defined in section 13.02, subdivision 7a, and providers as defined in section 144.291, subdivision 2(h), may only collect genetic information or a human biological specimen from an individual after that individual has given written informed consent that is signed and dated. The consent must include the following:

(1) the purposes within the organization of the collection which the individual providing the genetic information or human biological specimen is given written informed consent;

(2) the length of time the genetic information or human biological specimen will be retained; and

(3) any dissemination outside the organization of the genetic information or human biological specimen that will occur.

(b) Unless otherwise provided by law, a consent provided under this section is valid until revoked or as specified in the consent.

(c) Government entities, as defined in section 13.02, subdivision 7a, are exempt from the provisions of section 13.04, subdivision 2, for data collected under this section.

Sec. 5. Minnesota Statutes 2008, section 144.69, is amended to read:

144.69 CLASSIFICATION OF DATA ON INDIVIDUALS.

(a) Notwithstanding ~~any law to the contrary, including~~ section 13.05, subdivision 9, data ~~collected~~ on individuals collected by the cancer surveillance system, including the names and personal identifiers of persons required in section 144.68 to report, shall be private as defined in section 13.02 and may only be used for the purposes set forth in this section and sections 144.671, 144.672, and 144.68. Any disclosure other than is provided for in this section and sections 144.671, 144.672, and 144.68, is ~~declared to be~~ a misdemeanor ~~and punishable as such~~.

~~Except as provided by rule, and~~ (b) As part of an epidemiologic investigation, an ~~officer agent~~ or employee of the commissioner of health may interview patients named in any ~~such~~ report, or relatives of any ~~such~~ patient, only after the consent of the attending physician or surgeon from the patient is obtained. If the patient is deceased, or unable to provide consent, consent must be obtained from the patient's:

(1) legal guardian or health care agent, according to the designation in the patient's health care directive;

(2) spouse or registered domestic partner, if the patient does not have a legal guardian or health care agent;

(3) next of kin, if the patient does not have a legal guardian, health care agent, spouse or registered domestic partner, or other designated person under section 144.651, subdivision 26, paragraph (c); or

(4) personal representative, if the patient does not have a legal guardian, health care agent, spouse, registered domestic partner, or next of kin.

(c) The determination on consent is final once consent has been provided or refused.

(d) For purposes of this section, consent from the person required to report in section 144.68 is not needed before a request is made to the patient for an interview.

Sec. 6. Minnesota Statutes 2008, section 299C.155, subdivision 1, is amended to read:

Subdivision 1. ~~**Definition**~~ **Definitions.** (a) As used in this section, "DNA analysis" means the process through which deoxyribonucleic acid (DNA) in a human biological specimen is analyzed and compared with DNA from another human biological specimen for identification purposes.

(b) "Comparison report" means the data sent to law enforcement indicating whether there is a match following the DNA analysis.

(c) "Profile" means the data that document polymorphic loci and one gender marker that are the result of the DNA analysis.

(d) "Biological specimen" means the evidence or DNA sample provided for DNA analysis.

Sec. 7. Minnesota Statutes 2008, section 299C.155, subdivision 3, is amended to read:

Subd. 3. **DNA analysis and data bank.** The bureau shall adopt uniform procedures and protocols to maintain, preserve, and analyze human biological specimens for DNA. The bureau shall perform DNA analysis and make the comparison report available to law enforcement officials in connection with criminal investigations in which human biological specimens have been recovered. The bureau shall establish a centralized system to cross-reference data obtained from DNA analysis. ~~Data contained on the bureau's centralized system is private data on individuals, as that term is defined in section 13.02.~~ The bureau's centralized system may only be accessed by authorized law enforcement personnel and used solely for law enforcement identification purposes. ~~The remedies in section 13.08 apply to a violation of this subdivision.~~ The uniform procedures and protocols developed under this subdivision are not subject to the rulemaking provisions of chapter 14.

Sec. 8. Minnesota Statutes 2008, section 299C.155, subdivision 4, is amended to read:

Subd. 4. ~~**Record**~~ **Data classification.** ~~The bureau shall perform DNA analysis and make data obtained available to law enforcement officials in connection with criminal investigations in which human biological specimens have been recovered.~~ (a) Data in the comparison report are private data on individuals as defined in section 13.02. Upon request, the bureau shall ~~also~~ make the data comparison report available to the prosecutor and the ~~subject of the data~~ alleged perpetrator in any subsequent criminal prosecution of

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~~the subject. The results of the bureau's DNA analysis and related records are private data on individuals, as that term is defined in section 13.02, and may only be used for law enforcement identification purposes. The remedies in section 13.08 apply to a violation of this subdivision.~~ alleged perpetrator. A crime victim's profile may be shared with an alleged perpetrator only as required by the Rules of Criminal Procedure.

(b) Data contained on the bureau's centralized system are private data on individuals as defined in section 13.02, subdivision 12.

Sec. 9. Minnesota Statutes 2008, section 299C.155, is amended by adding a subdivision to read:

Subd. 5. **Access to specimens.** (a) The bureau shall make the biological specimens available to the prosecutor and the alleged perpetrator during the criminal proceeding as required by the Rules of Criminal Procedure. Once the criminal proceeding is concluded, any other access by the alleged perpetrator to the biological specimens shall require a court order.

(b) A crime victim may access their own biological specimens or those of an alleged perpetrator only by court order.

Sec. 10. Minnesota Statutes 2008, section 299C.155, is amended by adding a subdivision to read:

Subd. 6. **Remedies.** The remedies in section 13.08 and the penalties in section 13.09 apply to a violation of this section.

Sec. 11. **REPEALER.**

Minnesota Statutes 2008, section 13.386; and Minnesota Rules, part 4606.3306, are repealed.