

S.F. No. 1138 – Genetic Information Privacy Act

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Overview

S.F. 1138 establishes various protections for consumers who submit biological samples to direct-to-consumer genetic testing companies. This bill requires testing companies to obtain the consumer’s express consent, provide privacy notices to the consumer, and protect the security of the consumer’s genetic data from unauthorized disclosures.

Summary

Subdivision 1. Definitions. Defines key terms, including “biological sample,” “deidentified data,” “direct-to-consumer genetic testing company,” “express consent,” “genetic data,” and “genetic testing.”

Subdivision 2. Disclosure and consent requirements. Requires a direct-to-consumer genetic testing company to provide information regarding the company’s policies governing collection, use, and maintenance of genetic data, including a high-level privacy policy overview and a privacy notice.

Requires the company to obtain the consumer’s consent, which includes:

- initial express consent that provides the uses of genetic data collected and specifications on who has access to that data;
- separate express consent to disclose genetic data to any third party, use the data beyond the primary purpose, or retain any biological sample after initial testing;
- informed consent to transfer or disclose data to third parties for research purposes; and
- express consent for marketing purposes.

Requires the company to following valid legal process for disclosure of genetic data to law enforcement or any other governmental agency without the consumer’s express written consent. Requires the company to maintain a security program to protect the data and provide a process for the consumer to access or delete their data. Prohibits the company from disclosing the data without

the consumer's written consent to any entity offering health, life, or long-term care insurance or to the consumer's employer.

Subdivision 3. Enforcement. The commissioner of commerce may enforce this section pursuant to section 45.027, which authorizes the commissioner to bring an action in district court and impose civil penalties.

Subdivision 4. Limitations. Exempts protected health information collected by a covered entity or business associate and higher education institutions. For purposes of this exemption, "covered entity" means a health plan, a health care clearinghouse, and certain health care providers.