

Date of Hearing: August 18, 2020

ASSEMBLY COMMITTEE ON APPROPRIATIONS

Lorena Gonzalez, Chair

SB 980 (Umberg) – As Amended August 10, 2020

Policy Committee: Privacy and Consumer Protection Vote: 10 - 0

Urgency: No State Mandated Local Program: Yes Reimbursable: Yes

SUMMARY:

This bill creates the Genetic Information Privacy Act (GIPA). Specifically, this bill:

- 1) Requires a direct-to-consumer genetic testing company (GTC), or any company that collects or uses genetic materials obtained from a GTC, to provide policies and procedures regarding the collection, use and disclosure of genetic data, including a prominent and easily accessible privacy notice.
- 2) Requires a GTC to obtain a consumer's express consent to collect, transfer, disclose or store the consumer's genetic materials or market to a consumer based on the results of the consumer's genetic materials, except as specified.
- 3) Provides if a consumer revokes consent, the GTC must destroy the consumer's biological sample.
- 4) Requires a GTC to develop procedures that allow a consumer to easily access the consumer's genetic data, delete an account with the GTC and have the consumer's biological sample destroyed.
- 5) Prohibits a GTC from disclosing a consumer's genetic data or biological sample to any entity responsible for administering or making decisions regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment, or to any entity providing advice to an entity responsible for those functions, except as specified.
- 6) Imposes civil penalties between \$1,000 and \$10,000 for any violation of the GIPA and requires the Attorney General (AG), district attorney or city attorney to enforce the requirements of the GIPA.

FISCAL EFFECT:

- 1) Costs (General Fund (GF)) of \$208,000 in fiscal year (FY) 2020-21, 362,000 and \$362,000 annually thereafter for increased workload to prosecute violations of the GIPA. DOJ estimates the Consumer Protection Section would require one new deputy attorney general position and one new legal secretary to accommodate the workload required by this bill.
- 2) Cost pressures (General Fund (GF)/Trial Court Trust Fund) in the mid-hundreds of thousands of dollars annually to the courts in additional workload. This bill authorizes the DOJ, a district attorney, or a city attorney to file civil actions against GTCs for violations of the

requirements specified in this bill. If 20 cases are filed statewide resulting 20 hours of court time for each case, costs would be approximately \$382,400. Although courts are not funded on the basis of workload, increased pressure on the courts and staff may create a need for increased funding for staff and infrastructure. This is particularly true given that courts delayed hundreds of trials and civil motion during the COVID-19 pandemic resulting in a serious backlog that must be resolved. The Budget Act of 2020-21 allocated \$50 million dollars to the trial courts to address the backlog of cases resulting from suspension of operations during the early months of the COVID-19 pandemic.

COMMENTS:

1) **Purpose.** According to the author:

The evidence is clear: the laws regulating [GTCs] are inadequate and need to be strengthened to better protect consumers. Currently, at least [four] other states have enacted similar legislation due to the importance of protecting consumers' most sensitive information. By passing the Genetic Information Privacy Act, California will protect its consumers' most sensitive data.

2) **Background.** As genetic sequencing becomes less inexpensive and more accessible, the number of GTC have increased. In addition to various medical applications, the past several years have seen the rise of a growing industry genetic testing products. Businesses such as 23andMe and Ancestry.com market these products as opportunities to learn about a person's genetic makeup and familial connections. Use of genetic testing is also increasingly being used by law enforcement to solve cold cases.

Most notably, Joseph DeAngelo, also known as the Golden State Killer, was identified by submitting his DNA (when he was still unidentified) to a commercial genetic testing company and using existing connections to narrow down possible suspects and ultimately identify DeAngelo. While this is a useful application of commercial genetic testing, it raises significant privacy concerns. Additionally, the recently enacted California Consumer Protection Act (CCPA) broadly protects against disclosure of personal information, it does not specifically address issues pertaining to GTC. Finally, although collection of DNA from an arrestee for inclusion in the Combined DNA Index System (CODIS) is generally permissible under the Fourth Amendment, it is not clear whether law enforcement would need a warrant to access information held by a GTC. This bill requires GTC to provide specific information to customers that their genetic material may be accessed by law enforcement.

3) **Arguments in Support.** According to Consumer Reports:

With increasing developments of at-home healthcare solutions, testing, and products, it is important to ensure that our laws protect consumers in the rapidly changing market.... By curbing unauthorized disclosure and curbing secondary uses of this sensitive data, this bill would extend important privacy protections to consumers.

- 4) **Prior Legislation.** SB 222 (Padilla), of the 2013-2014 Legislative Session, would have prohibited any person, as defined, from obtaining, analyzing, retaining, or disclosing genetic information without the written authorization of the individual to whom the information pertains. SB 222 was held on the Senate Appropriations Committee's suspense file.

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