

Introduced by Senator Padilla

February 11, 2013

An act to add Section 56.19 to the Civil Code, relating to genetic information.

LEGISLATIVE COUNSEL'S DIGEST

SB 222, as amended, Padilla. Genetic information: privacy.

Existing law prohibits discrimination on the basis of an individual's genetic information. Existing law protects the genetic test result contained in the medical records of an applicant to, or enrollee of, a health care service plan. Existing law establishes civil and criminal penalties for the negligent or willful disclosure of a persons genetic test results, as specified.

This bill would declare that an individual's genetic information is protected by the right of privacy. The bill would prohibit any person from collecting, storing, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, and would include related findings and declarations. The bill would establish civil and criminal penalties for a violation of this prohibition. By creating new crimes, this bill would impose a state-mandated local program.

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act for a specified reason.

~~This bill would state the intent of the Legislature to enact legislation that would protect individuals from the unauthorized use of their genetic information, ensure that genetic information is personal information that is not collected, stored, or disclosed without the individual's authorization, provide protections for the collection, storage, and authorized use of genetic information, and promote the use of genetic information for legitimate reasons, including, but not limited to, health care, research, advancement of medicine, and educational purposes, as the field of genomics advances.~~

~~This bill would also make findings and declarations regarding genetic privacy.~~

~~Vote: majority. Appropriation: no. Fiscal committee: ~~no~~-yes.
State-mandated local program: ~~no~~-yes.~~

The people of the State of California do enact as follows:

- 1 SECTION 1. The Legislature finds and declares all of the
- 2 following:
- 3 (a) On October 11, 2012, the Presidential Commission for the
- 4 Study of Bioethical Issues (commission) released a report titled
- 5 “Privacy and Progress in Whole Genome Sequencing,”
- 6 recommending the adoptions of policies to help ensure privacy
- 7 and security, as the field of genomics advances.
- 8 (b) Various national and state policies are in place to protect
- 9 personally identifiable health information and records.
- 10 (c) The commission urges federal and state governments to
- 11 ensure a consistent floor of privacy protections covering whole
- 12 genome sequencing data regardless of how they were obtained.
- 13 (d) Policies should protect individual genetic information by
- 14 prohibiting the unauthorized use of surreptitious collection.
- 15 (e) It is the intent of the Legislature to enact legislation that
- 16 would protect individuals from the unauthorized collection, storage,
- 17 and disclosure of their genetic information.
- 18 (f) It is the intent of the Legislature to enact legislation that
- 19 would ensure that genetic information is personal information that
- 20 is not collected, stored, or disclosed without the individual's
- 21 authorization.
- 22 (g) It is the intent of the Legislature to enact legislation that
- 23 would provide protections for the collection, storage, and
- 24 authorized use of genetic information.

1 (h) It is the intent of the Legislature to enact legislation that
2 would promote the use of genetic information for legitimate
3 reasons, including, but not limited to, health care, research,
4 advancement of medicine, and educational purposes, as the field
5 of genomics advances.

6 *SEC. 2. Section 56.19 is added to the Civil Code, to read:*

7 *56.19. (a) Genetic information is protected by the right of*
8 *privacy pursuant to Section 1 of Article I of the California*
9 *Constitution and, notwithstanding subdivision (c) of Section 56.10,*
10 *or any other law, shall not be collected, stored, analyzed, or*
11 *disclosed without the written authorization of the individual to*
12 *whom the information pertains.*

13 *(b) Any person who negligently violates subdivision (a) shall*
14 *be assessed a civil penalty in an amount not to exceed one thousand*
15 *dollars (\$1,000) plus court costs, as determined by the court, which*
16 *penalty and costs shall be paid to the individual to whom the*
17 *genetic information pertains.*

18 *(c) Any person who willfully violates subdivision (a) shall be*
19 *assessed a civil penalty in an amount not less than one thousand*
20 *dollars (\$1,000) and not more than five thousand dollars (\$5,000)*
21 *plus court costs, as determined by the court, which penalty and*
22 *costs shall be paid to the individual to whom the genetic*
23 *information pertains.*

24 *(d) Any person who willfully or negligently violates subdivision*
25 *(a), where the violation results in economic, bodily, or emotional*
26 *harm to the individual to whom the genetic information pertains,*
27 *is guilty of a misdemeanor punishable by a fine not to exceed ten*
28 *thousand dollars (\$10,000).*

29 *(e) In addition to the penalties listed in subdivisions (b) and (c),*
30 *a person who commits an act described in subdivision (b) or (c)*
31 *shall be liable to the person to whom the genetic information*
32 *pertains for all actual damages, including damages for economic,*
33 *bodily, and emotional harm that is proximately caused by that act.*

34 *(f) Each violation of this section is a separate and actionable*
35 *offense.*

36 *(g) (1) No person or entity who sends or discloses genetic*
37 *information in a good faith attempt to comply with this section*
38 *shall be liable under this section for the conduct of the recipient.*

1 (2) *No person or entity that receives genetic information in a*
2 *good faith attempt to comply with this section shall be liable under*
3 *this section for the conduct of the sender or discloser.*

4 *SEC. 3. No reimbursement is required by this act pursuant to*
5 *Section 6 of Article XIII B of the California Constitution because*
6 *the only costs that may be incurred by a local agency or school*
7 *district will be incurred because this act creates a new crime or*
8 *infraction, eliminates a crime or infraction, or changes the penalty*
9 *for a crime or infraction, within the meaning of Section 17556 of*
10 *the Government Code, or changes the definition of a crime within*
11 *the meaning of Section 6 of Article XIII B of the California*
12 *Constitution.*