

**Introduced by Senator Padilla**February 11, 2013

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An act relating to genetic information.

## LEGISLATIVE COUNSEL'S DIGEST

SB 222, as introduced, 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 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.  
State-mandated local program: no.

*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.
- 25 (h) It is the intent of the Legislature to enact legislation that  
26 would promote the use of genetic information for legitimate  
27 reasons, including, but not limited to, health care, research,  
28 advancement of medicine, and educational purposes, as the field  
29 of genomics advances.