Introduced by Senator Padilla

February 23, 2012

An act to amend Sections 105280 and 109910 of the Health and Safety Code, relating to public health. An act to add Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code, relating to genetic information.

LEGISLATIVE COUNSEL’S DIGEST

SB 1267, as amended, Padilla. Public health—Genetic Information Privacy Act.

Existing law prohibits discrimination on the basis of genetic information under various provisions of law, including, among others, the Unruh Civil Rights Act and the California Fair Employment and Housing Act. Existing law prohibits discrimination in the enrollment of health insurance plans on the basis of an individual’s genetic characteristics, as defined. Existing law also imposes prohibitions on the disclosure by a health care service plan of the results of a test for a genetic characteristic contained in an applicant’s or enrollee’s medical records.

This bill would establish the Genetic Information Privacy Act, which would provide that an individual’s genetic information, as defined, is protected by the right of privacy. The bill would, notwithstanding any other law, prohibit any person, as defined, from obtaining, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, as specified, and would establish civil and criminal penalties for a violation of this prohibition, as specified. However, this bill would exempt from these prohibitions
and penalties law enforcement officials in the execution of their official
duties, hospitals, laboratories, and physicians carrying out
court-ordered tests, licensed health care professionals in medical
emergencies, coroners and medical examiners in the execution of their
official duties, any screening of newborn infants required by state or
federal law, and disaggregated and anonymized data, as defined, that
was either collected before the bill’s enactment or if written consent is
obtained. By creating new crimes, the 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
because it creates new crimes.

Existing law requires the State Department of Public Health to
administer various public health programs, including the childhood lead
poisoning prevention program and the food safety inspection program.

This bill would make technical, nonsubstantive changes to these
provisions:

State-mandated local program: no-yes.

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

SECTION 1. Chapter 2.6 (commencing with Section 56.18) is
added to Part 2.6 of Division 1 of the Civil Code, to read:

CHAPTER 2.6. GENETIC PRIVACY

56.18. (a) This chapter shall be known, and may be cited, as
the Genetic Information Privacy Act.

(b) For purposes of this chapter, the following definitions apply:
(1) “Anonymized” means data from which an individual’s
identifying information has been removed.

(2) “DNA sample” means any human biological specimen that
is obtained or retained for the purpose of extracting and analyzing
DNA to perform a genetic test.

(3) “Genetic characteristic” includes a gene, chromosome, or
alteration thereof that may be tested to determine the existence or
risk of a disease, disorder, trait, propensity, or syndrome, or to identify an individual or a blood relative.

(4) “Genetic information” means, with respect to an individual, information about the genetic tests of the individual, the genetic tests of the individual’s family members, and the manifestation of a disease or disorder in family members of the individual. The term includes a request for, or receipt of, genetic services, or participation in clinical research that includes genetic services, by the individual or a family member of the individual.

(5) “Genetic service” means a genetic test, genetic education, or genetic counseling, including obtaining, interpreting, or assessing genetic information.

(6) “Genetic test” means a test for determining the presence or absence of genetic characteristics in an individual or the individual’s blood relatives, including tests of nucleic acids such as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins in order to diagnose or determine a genetic characteristic.

(7) “Person” means an individual, partnership, corporation, association, business, business trust, or legal representative of an organization.

56.19. (a) Genetic information is protected by the right of privacy, and, notwithstanding subdivision (c) of Section 56.10, or any other law, shall not be obtained, analyzed, retained, or disclosed without the written authorization of the individual pursuant to subdivision (g).

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

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

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

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

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

(g) The written authorization required by this section shall satisfy all of the following requirements:

(1) Is written in plain language and is in a typeface no smaller than 14-point type.
(2) Is dated and signed by the individual or a person authorized to act on behalf of the individual.
(3) Specifies the types of persons authorized to obtain, analyze, or disclose genetic information about the individual.
(4) Specifies the nature of the genetic information authorized to be obtained, analyzed, or disclosed.
(5) States the name or functions of the persons or entities authorized to obtain, analyze, or receive the information.
(6) Specifies the purposes for which the information is collected.
(7) Specifies the length of time the authorization shall remain valid.
(8) Specifies whether the genetic information may be used for any commercial purpose.
(9) Specifies whether the genetic information shall remain identifiable or shall be made nonidentifiable.
(10) If the information is retained, specifies the manner in which the information shall be stored.
(11) Requires the destruction of the genetic information and sample after the specific purpose for which the consent was granted has been fulfilled.
(12) Permits the individual to limit access to the information to a certain person or persons.
(13) Permits the individual to revoke his or her consent in writing at any time.
(14) Advises the individual signing the authorization of the right to receive a copy of the authorization. Written authorization is required for each separate disclosure of the genetic information.
(h) This section shall not apply to the following:

1. A law enforcement official in the execution of his or her official duties.
2. A hospital, laboratory, or physician carrying out court-ordered tests for genetic information.
3. A licensed health care professional, as defined in Section 56.05, in medical emergencies.
4. A coroner or medical examiner in the execution of his or her official duties.
5. Disaggregated and anonymized data that was collected before the enactment of the act adding this section.
6. Any screening of newborn infants required by state or federal law.
7. Disaggregated and anonymized data if written consent under subdivision (g) is obtained.

SEC. 2. No reimbursement is required by this act pursuant to Section 6 of Article XIII B of the California Constitution because the only costs that may be incurred by a local agency or school district will be incurred because this act creates a new crime or infraction, eliminates a crime or infraction, or changes the penalty for a crime or infraction, within the meaning of Section 17556 of the Government Code, or changes the definition of a crime within the meaning of Section 6 of Article XIII B of the California Constitution.

SECTION 1. Section 105280 of the Health and Safety Code is amended to read:

105280. For purposes of this chapter, the following definitions apply:

(a) “Appropriate case management” means health care referrals, environmental assessments, and educational activities, performed by the appropriate person, professional, or entity, necessary to reduce a child’s exposure to lead and the consequences of the exposure, as determined by the United States Centers for Disease Control, or as determined by the department pursuant to Section 105300.

(b) “Lead poisoning” means the disease present when the concentration of lead in whole venous blood reaches or exceeds levels constituting a health risk, as specified in the most recent United States Centers for Disease Control guidelines for lead poisoning, as determined by the department, or when the
concentration of lead in whole venous blood reaches or exceeds levels constituting a health risk as determined by the department pursuant to Section 105300.

(e) “Department” means the State Department of Public Health.

(d) “Health assessment” has the same meaning as prescribed in Section 6800 of Title 17 of the California Code of Regulations.

(e) “Screen” means the medical procedure by which the concentration of lead in whole venous blood is measured.

(f) “Health care” means the identification, through evaluation and screening, if indicated, of lead poisoning, as well as any followup medical treatment necessary to reduce the elevated blood lead levels.

(g) “Environmental lead contamination” means the persistent presence of lead in the environment, in quantifiable amounts, that results in ongoing and chronic exposure to children.

SEC. 2. Section 109910 of the Health and Safety Code is amended to read:

109910. “Department” means the State Department of Public Health.