

Privacy and Genetic Testing

This Act makes it illegal to perform DNA analysis on a sample, retain a DNA sample or the results of a DNA analysis, or disclose the results of a DNA analysis unless the person has first obtained the informed and written consent of the person, or the person's legal guardian or authorized representative, for the collection, analysis, retention, or disclosure. A DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.

The prohibitions of this section do not apply to DNA samples collected and analyses conducted for law enforcement purposes, including the identification of perpetrators and the investigation of crimes and the identification of missing or unidentified persons or deceased individuals, for determining paternity, or to perform newborn screenings required by state and federal law or for the purpose of emergency medical treatment.

A person may revoke or amend their informed and written consent at any time. A person may bring a civil action against a person who collects a DNA sample from the person, performs a DNA analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the results of a DNA analysis in violation of this Act. In addition to the actual damages suffered by the person, a person violating this chapter shall be liable to the person for damages in the amount of \$5,000 or, if the violation resulted in profit or monetary gain to the violator, \$100,000.

Submitted as:

Alaska

[SB 217](#)

Status: Enacted into law in 2004.

Suggested State Legislation

1 (Title, enacting clause, etc.)

2

3 Section 1. [*Short Title.*] This Act may be cited as “An Act to Address Genetic Privacy
4 and Genetic Testing.”

5

6 Section 2. [*Definitions.*] As used in this Act:

7 (A) “DNA” means deoxyribonucleic acid, including mitochondrial DNA,
8 complementary DNA, and DNA derived from ribonucleic acid;

9 (B) “DNA analysis” means DNA or genetic typing and testing to determine the presence
10 or absence of genetic characteristics in an individual, including tests of nucleic acids or
11 chromosomes in order to diagnose or identify a genetic characteristic; “DNA analysis” does not
12 include a routine physical measurement, a test for drugs, alcohol, cholesterol, or the human
13 immunodeficiency virus, a chemical, blood, or urine analysis, or any other diagnostic test that is
14 widely accepted and in use in clinical practice;

15 (C) “Genetic characteristic” includes a gene, chromosome, or alteration of a gene or
16 chromosome that may be tested to determine the existence or risk of a disease, disorder, trait,
17 propensity, or syndrome, or to identify an individual or a blood relative. “Genetic characteristic”
18 does not include family history or a genetically transmitted characteristic whose existence or
19 identity is determined other than through a genetic test.

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21 Section 3. [*Genetic Privacy, Genetic Testing.*]

22 (a) Except as provided in (b) of this section,

23 (1) A person may not collect a DNA sample from a person, perform a DNA
24 analysis on a sample, retain a DNA sample or the results of a DNA analysis, or disclose the
25 results of a DNA analysis unless the person has first obtained the informed and written consent
26 of the person, or the person's legal guardian or authorized representative, for the collection,
27 analysis, retention, or disclosure;

28 (2) A DNA sample and the results of a DNA analysis performed on the sample
29 are the exclusive property of the person sampled or analyzed.

30 (b) The prohibitions of (a) of this section do not apply to DNA samples collected and
31 analyses conducted:

32 (1) The [Department of Public Safety DNA Registration System];

33 (2) For a law enforcement purpose, including the identification of perpetrators and
34 the investigation of crimes and the identification of missing or unidentified persons or deceased
35 individuals;

36 (3) For determining paternity;

37 (4) To screen newborns as required by state or federal law, and

38 (5) For the purpose of emergency medical treatment.

39 (c) A general authorization for the release of medical records or medical information
40 may not be construed as the informed and written consent required by this section. The
41 [Department of Health and Social Services] may by regulation adopt a uniform informed and
42 written consent form to assist persons in meeting the requirements of this section. A person
43 using that uniform informed and written consent is exempt from civil or criminal liability for
44 actions taken under the consent form. A person may revoke or amend their informed and written
45 consent at any time.

46

47 Section 4. [*Private Right of Action.*] A person may bring a civil action against a person
48 who collects a DNA sample from the person, performs a DNA analysis on a sample, retains a
49 DNA sample or the results of a DNA analysis, or discloses the results of a DNA analysis in
50 violation of this Act. In addition to the actual damages suffered by the person, a person violating
51 this Act shall be liable to the person for damages in the amount of [\$5,000] or, if the violation
52 resulted in profit or monetary gain to the violator, [\$100,000].

53

54 Section 5. [*Criminal Penalty.*]

55 (a) A person commits the crime of unlawful DNA collection, analysis, retention, or
56 disclosure if the person knowingly collects a DNA sample from a person, performs a DNA
57 analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the
58 results of a DNA analysis in violation of this Act.

59 (b) In this section, "knowingly" has the meaning given in [insert citation].

60 (c) Unlawful DNA collection, analysis, retention, or disclosure is a [class A
61 misdemeanor].

62

63 Section 5. [*Severability.*] [Insert severability clause.]

64

65 Section 6. [*Repealer.*] [Insert repealer clause.]

66

67 Section 7. [*Effective Date.*] [Insert effective date.]