

# 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

(Title, enacting clause, etc.)

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

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

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(a) “DNA” means deoxyribonucleic acid, including mitochondrial DNA, complementary  
6 DNA, and DNA derived from ribonucleic acid;

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

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

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19 Section 3. [*Genetic Privacy, Genetic Testing.*]  
20 (a) Except as provided in (b) of this section,  
21 (1) A person may not collect a DNA sample from a person, perform a DNA  
22 analysis on a sample, retain a DNA sample or the results of a DNA analysis, or disclose the  
23 results of a DNA analysis unless the person has first obtained the informed and written consent  
24 of the person, or the person's legal guardian or authorized representative, for the collection,  
25 analysis, retention, or disclosure;  
26 (2) A DNA sample and the results of a DNA analysis performed on the sample  
27 are the exclusive property of the person sampled or analyzed.  
28 (b) The prohibitions of (a) of this section do not apply to DNA samples collected and  
29 analyses conducted:  
30 (1) The [Department of Public Safety DNA Registration System];  
31 (2) For a law enforcement purpose, including the identification of perpetrators and  
32 the investigation of crimes and the identification of missing or unidentified persons or deceased  
33 individuals;  
34 (3) For determining paternity;  
35 (4) To screen newborns as required by state or federal law, and  
36 (5) For the purpose of emergency medical treatment.  
37 (c) A general authorization for the release of medical records or medical information  
38 may not be construed as the informed and written consent required by this section. The  
39 [Department of Health and Social Services] may by regulation adopt a uniform informed and  
40 written consent form to assist persons in meeting the requirements of this section. A person  
41 using that uniform informed and written consent is exempt from civil or criminal liability for  
42 actions taken under the consent form. A person may revoke or amend their informed and written  
43 consent at any time.  
44

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

52 Section 5. [*Criminal Penalty.*]  
53 (a) A person commits the crime of unlawful DNA collection, analysis, retention, or  
54 disclosure if the person knowingly collects a DNA sample from a person, performs a DNA  
55 analysis on a sample, retains a DNA sample or the results of a DNA analysis, or discloses the  
56 results of a DNA analysis in violation of this Act.  
57 (b) In this section, “knowingly” has the meaning given in [insert citation].  
58 (c) Unlawful DNA collection, analysis, retention, or disclosure is a [class A  
59 misdemeanor].  
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61 Section 6. [*Severability.*] [Insert severability clause.]  
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63 Section 7. [*Repealer.*] [Insert repealer clause.]  
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65 Section 8. [*Effective Date.*] [Insert effective date.]