

**SENATE BILL NO. 217**

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-THIRD LEGISLATURE - FIRST SESSION

BY SENATOR OLSON

**Introduced: 5/9/03**

**Referred: Health, Education and Social Services, Judiciary**

**A BILL**

**FOR AN ACT ENTITLED**

1 **"An Act relating to genetic privacy; and amending Rule 82, Alaska Rules of Civil**  
2 **Procedure, and Rule 508, Alaska Rules of Appellate Procedure."**

3 **BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

4 **\* Section 1.** AS 18 is amended by adding a new chapter to read:

5 **Chapter 13. Genetic Privacy.**

6 **Sec. 18.13.010. Legislative findings; purposes.** (a) The legislature finds that

7 (1) the DNA molecule contains information about the probable  
8 medical future of an individual and the individual's blood relatives; this information is  
9 written in a code that is rapidly being deciphered;

10 (2) genetic information is uniquely private and personal information  
11 that generally should not be collected, retained, or disclosed without the individual's  
12 authorization;

13 (3) the improper collection, retention, or disclosure of genetic  
14 information can lead to significant harm to an individual and the individual's blood

1 relatives, including stigmatization and discrimination in areas such as employment,  
2 education, health care, and insurance;

3 (4) an analysis of an individual's DNA provides information not only  
4 about the individual, but also about blood relatives of the individual, with the potential  
5 for affecting family privacy, including reproductive decisions;

6 (5) current legal protections for medical information, tissue samples,  
7 and DNA samples are inadequate to protect genetic privacy; and

8 (6) laws for the collection, storage, and use of identifiable DNA  
9 samples and private genetic information obtained from those samples are needed both  
10 to protect individual and family privacy and to permit and encourage legitimate  
11 scientific and medical research.

12 (b) The purposes of this chapter are as follows:

13 (1) to define the rights of individuals whose genetic information is  
14 collected, retained, or disclosed and the rights of the individuals' blood relatives;

15 (2) to define the circumstances under which an individual may be  
16 subjected to genetic testing;

17 (3) to define the circumstances under which an individual's genetic  
18 information may be collected, retained, or disclosed;

19 (4) to protect against discrimination by an insurer or employer based  
20 upon an individual's genetic characteristics; and

21 (5) to define the circumstances under which a DNA sample or genetic  
22 information may be used for research.

23 **Sec. 18.13.020. Informed consent for obtaining genetic information.** (a) A  
24 person may not obtain genetic information from an individual or from an individual's  
25 DNA sample without first obtaining informed consent of the individual or the  
26 individual's representative, except

27 (1) as authorized by AS 44.41.035 or comparable provisions of another  
28 jurisdiction relating to the identification of persons, or for the purpose of establishing  
29 the identity of a person in the course of an investigation conducted by a law  
30 enforcement agency, the Department of Law, or a medical examiner;

31 (2) for anonymous research conducted after notification as provided in

1 AS 18.13.030(b);

2 (3) as permitted by regulations of the Department of Health and Social  
3 Services for identification of, or testing to benefit blood relatives of, deceased  
4 individuals;

5 (4) as permitted by regulations of the Department of Health and Social  
6 Services for newborn screening procedures; or

7 (5) as authorized by statute for the purpose of establishing paternity.

8 (b) Except as provided in (c) of this section, a physician licensed under  
9 AS 08.64 shall seek the informed consent of the individual or the individual's  
10 representative for the purposes of (a) of this section in the manner the physician  
11 obtains informed consent for medical procedures. Except as provided in (c) of this  
12 section, any other licensed health care provider or facility must seek the informed  
13 consent of the individual or the individual's representative for the purposes of (a) of  
14 this section in a manner substantially similar to the manner physicians obtain informed  
15 consent for medical procedures.

16 (c) A person conducting research shall seek the informed consent of the  
17 individual or the individual's representative for the purposes of (a)(2) of this section in  
18 the manner provided by AS 18.13.030.

19 (d) Except as provided in AS 44.41.035, any person not described in (b) or (c)  
20 of this section must seek the informed consent of the individual or the individual's  
21 representative for the purposes of (a)(3) - (5) of this section in the manner provided by  
22 regulations adopted by the Department of Health and Social Services.

23 (e) The Department of Health and Social Services may not adopt regulations  
24 under (a)(4) of this section that would require the providing of a DNA sample for the  
25 purpose of obtaining complete genetic information used to screen all newborns.

26 **Sec. 18.13.030. Individual's rights in genetic information; retention of**  
27 **information; destruction of information.** (a) Subject to the other provisions of this  
28 chapter, an individual's genetic information and DNA sample are private and must be  
29 protected, and an individual has a right to the protection of that privacy. Any person  
30 authorized by law or by an individual or an individual's representative to obtain,  
31 retain, or use an individual's genetic information or any DNA sample shall maintain

1 the confidentiality of the information or sample and protect the information or sample  
2 from unauthorized disclosure or misuse.

3 (b) A person may use an individual's DNA sample or genetic information for  
4 anonymous research only if the individual was notified the sample or genetic  
5 information may be used for anonymous research and the individual did not, at the  
6 time of notification, request that the sample not be used for anonymous research. The  
7 Department of Health and Social Services shall adopt regulations to implement this  
8 subsection after considering similar federal regulations.

9 (c) A person may not retain another individual's genetic information or DNA  
10 sample without first obtaining authorization from the individual or the individual's  
11 representative, unless retention is

12 (1) authorized by AS 44.41.035 or comparable provisions of another  
13 jurisdiction relating to identification of persons, or is necessary for the purpose of a  
14 criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a  
15 child fatality review by a multidisciplinary child protection team;

16 (2) authorized by specific court order under rules adopted by the  
17 Alaska Supreme Court for civil actions;

18 (3) permitted by regulations of the Department of Health and Social  
19 Services for identification of, or testing to benefit blood relatives of, deceased  
20 individuals;

21 (4) permitted by regulations of the Department of Health and Social  
22 Services for newborn screening procedures; or

23 (5) for anonymous research conducted after notification under (b) of  
24 this section.

25 (d) The DNA sample of an individual from which genetic information has  
26 been obtained shall be destroyed promptly upon the specific request of that individual  
27 or the individual's representative, unless retention is

28 (1) authorized by AS 44.41.035 or comparable provisions of another  
29 jurisdiction relating to identification of persons, or is necessary for the purpose of a  
30 criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a  
31 child fatality review by a multidisciplinary child protection team;

1 (2) authorized by specific court order under rules adopted by the  
2 Alaska Supreme Court for civil actions; or

3 (3) for anonymous research conducted after notification under (b) of  
4 this section.

5 (e) A DNA sample from an individual that is the subject of a research project,  
6 other than an anonymous research project, shall be destroyed promptly upon  
7 completion of the project or withdrawal of the individual from the project, whichever  
8 occurs first, unless the individual or the individual's representative directs otherwise  
9 by informed consent.

10 (f) A DNA sample from an individual for insurance or employment purposes  
11 shall be destroyed promptly after the purpose for which the sample was obtained has  
12 been accomplished unless retention is authorized by specific court order under rules  
13 adopted by the Alaska Supreme Court.

14 (g) An individual or an individual's representative, promptly upon request,  
15 may inspect, request correction of, and obtain genetic information from the records of  
16 the individual, unless the genetic information has been made anonymous by  
17 destruction of all information that could allow disclosure of the identity of the  
18 individual who provided the sample or the identity of the individual's blood relatives.

19 (h) Subject to the other provisions of this chapter, and to policies adopted by  
20 the person in possession of a DNA sample, an individual or the individual's  
21 representative may request that the individual's DNA sample be made available for  
22 additional genetic testing for medical diagnostic purposes. If the individual is deceased  
23 and has not designated a representative to act on behalf of the individual after death, a  
24 request under this subsection may be made by the closest surviving blood relative of  
25 the decedent or, if there is more than one surviving blood relative of the same degree  
26 of relationship to the decedent, by the majority of the surviving closest blood relatives  
27 of the decedent.

28 (i) The Department of Health and Social Services shall coordinate the  
29 implementation of this section.

30 (j) This section applies only to genetic information that can be identified as  
31 belonging to an individual or the individual's blood relative. This section does not

1 apply to a law, contract, or other arrangement that determines a person's rights to  
 2 compensation relating to substances or information derived from an individual's DNA  
 3 sample.

4 **Sec. 18.13.040. Disclosure of genetic information; exceptions.** (a)  
 5 Regardless of the manner of receipt or the source of genetic information, including  
 6 information received from an individual or a blood relative of the individual, a person  
 7 may not disclose or be compelled, by subpoena or any other means, to disclose the  
 8 identity of an individual upon whom a genetic test has been performed or the identity  
 9 of a blood relative of the individual, or to disclose genetic information about the  
 10 individual or a blood relative of the individual in a manner that permits identification  
 11 of the individual or a blood relative of the individual, unless disclosure is

12 (1) authorized by AS 44.41.035 or comparable provisions of another  
 13 jurisdiction relating to identification of persons, or is necessary for the purpose of a  
 14 criminal or death investigation, a criminal or juvenile proceeding, an inquest, or a  
 15 child fatality review by a multidisciplinary child protection team;

16 (2) required by specific court order entered under rules adopted by the  
 17 Alaska Supreme Court for civil actions;

18 (3) authorized by statute for the purpose of establishing paternity;

19 (4) specifically authorized by the tested individual or the tested  
 20 individual's representative by signing a consent form prescribed by regulations of the  
 21 Department of Health and Social Services; or

22 (5) for identification of, or testing to benefit blood relatives of,  
 23 deceased individuals.

24 (b) The prohibitions of this section apply to redisclosure by a person after  
 25 another person has disclosed genetic information or the identity of an individual upon  
 26 whom a genetic test has been performed, or has disclosed genetic information or the  
 27 identity of a blood relative of the individual.

28 (c) A release or publication is not a disclosure if

29 (1) it involves a good faith belief by the person who caused the release  
 30 or publication that the person was not in violation of this section;

31 (2) it is not due to intentional conduct or gross negligence;

1 (3) it is corrected in the manner described in AS 18.13.050(c);

2 (4) the correction with respect to genetic information is completed  
3 before the information is read or heard by a third party; and

4 (5) the correction with respect to DNA samples is completed before  
5 the sample is retained or genetically tested by a third party.

6 **Sec. 18.13.050. Private right of action; remedies; affirmative defense;**  
7 **attorney fees.** (a) An individual or an individual's blood relative, representative, or  
8 estate may bring a civil action against a person who violates a provision of this  
9 chapter.

10 (b) For a violation of this chapter, the court shall award the greater of actual  
11 damages or

12 (1) \$1,000 for an inadvertent violation that does not arise out of the  
13 negligence of the defendant;

14 (2) \$5,000 for a negligent violation;

15 (3) \$100,000 for a knowing or reckless violation;

16 (4) \$150,000 for a knowing violation based on a fraudulent  
17 misrepresentation; or

18 (5) \$250,000 for a knowing violation committed with intent to sell,  
19 transfer, or use for commercial advantage, personal gain, or malicious harm.

20 (c) It is an affirmative defense to an action described in (b)(1) or (2) of this  
21 section that the defendant corrected the violation through destruction of illegally  
22 retained or obtained samples or information, or took other action to correct the  
23 violation, if the correction was completed within 120 days after the defendant knew or  
24 should have known that the violation occurred.

25 (d) The court may provide the equitable relief it considers necessary or proper.

26 (e) The court may award attorney fees to a defendant only if the court finds  
27 that the plaintiff did not have an objectively reasonable basis for asserting a claim or  
28 for appealing an adverse decision of the trial court.

29 (f) An action authorized by (a) of this section must be commenced within  
30 three years after the date the plaintiff knew or should have known of the violation, but  
31 in no instance more than 10 years after the date of the violation.

1 (g) A plaintiff may recover damages provided by this section for each  
2 violation by a defendant.

3 **Sec. 18.13.060. Criminal penalty.** (a) A person commits the crime of  
4 unlawfully obtaining, retaining, or disclosing genetic information if the person, with  
5 criminal negligence, obtains, retains, or discloses genetic information in violation of  
6 this chapter.

7 (b) In this section, "criminal negligence" has the meaning given in  
8 AS 11.81.900.

9 (c) Unlawfully obtaining, retaining, or disclosing genetic information is a  
10 Class A misdemeanor.

11 **Sec. 18.13.070. Enforcement; Department of Law; intervention.** (a) The  
12 attorney general may bring an action against a person who violates this chapter. In  
13 addition to remedies otherwise available or provided in this chapter, the court shall  
14 award to the attorney general the costs of this investigation.

15 (b) The attorney general may intervene in a civil action brought under this  
16 chapter if the attorney general certifies that, in the opinion of the attorney general, the  
17 action is of general public importance. In the action, the attorney general shall be  
18 entitled to the same relief as if the attorney general had instituted the action under this  
19 section.

20 **Sec. 18.13.080. Department of Health and Social Services regulations;**  
21 **procedures.** (a) The Department of Health and Social Services shall adopt regulations  
22 for conducting research using DNA samples, genetic testing, and genetic information.  
23 Regulations establishing minimum research standards must conform to the Federal  
24 Policy for the Protection of Human Subjects, 45 C.F.R. 46, that is current at the time  
25 the rules are adopted. The regulations may be changed from time to time as may be  
26 necessary.

27 (b) The regulations adopted by the Department of Health and Social Services  
28 must address the operation and appointment of institutional review boards. The  
29 regulations must conform to the compositional and operational standards for  
30 institutional review boards contained in the Federal Policy for the Protection of  
31 Human Subjects that is current at the time the regulations are adopted. The

1 regulations must require that research conducted under (a) of this section be conducted  
2 with the approval of an institutional review board.

3 (c) Persons proposing to conduct anonymous research or genetic research that  
4 is otherwise thought to be exempt from review shall, before conducting the research,  
5 obtain a determination from an institutional review board that the proposed research is  
6 exempt from review.

7 (d) A person proposing to conduct research under this section, including  
8 anonymous research, shall disclose to an institutional review board the proposed use  
9 of DNA samples, genetic testing, or genetic information.

10 (e) The Department of Health and Social Services shall adopt regulations  
11 requiring that all institutional review boards operating under (b) of this section register  
12 with the department.

13 (f) Research conducted in accordance with this section is rebuttably presumed  
14 to comply with this chapter.

15 (g) In cases in which informed consent is required by this chapter or the  
16 Federal Policy for the Protection of Human Subjects, samples collected before the  
17 effective date of this Act with blanket informed consent for research may be used for  
18 genetic research without specific informed consent, but samples obtained after the  
19 effective date of this Act must have specific informed consent from the individual for  
20 genetic research.

21 (h) Except as otherwise allowed by regulation of the Department of Health  
22 and Social Services, if DNA samples or genetic information obtained for either  
23 clinical or research purposes is used in research, a person may not recontact the  
24 individual or the individual's physician by using research information with personal  
25 identifiers. The Department of Health and Social Services shall adopt by regulation  
26 criteria for recontacting an individual or an individual's physician. In adopting the  
27 criteria, the department shall consider the recommendations of national organizations  
28 such as those created by executive order by the President of the United States.

29 **Sec. 18.13.100. Definitions.** In this chapter,

30 (1) "anonymous research" means scientific or medical research  
31 conducted in such a manner that the identity of an individual who has provided a

1 sample, or the identity of an individual from whom genetic information has been  
2 obtained or the identity of the individual's blood relatives, cannot be determined;

3 (2) "blanket informed consent" means that the individual has  
4 consented to the use of the individual's DNA sample or health information for any  
5 future research, but has not been provided with a description of or consented to the use  
6 of the sample in genetic research or any specific genetic research project;

7 (3) "blood relative" means a person who is

8 (A) related by blood to an individual; and

9 (B) a parent, sibling, son, daughter, grandparent, grandchild,  
10 aunt, uncle, first cousin, niece, or nephew of the individual;

11 (4) "clinical" means relating to or obtained through the actual  
12 observation, diagnosis, or treatment of patients and not through research;

13 (5) "disclose" means to release, publish, or otherwise make known to a  
14 third party a DNA sample or genetic information;

15 (6) "DNA" means deoxyribonucleic acid;

16 (7) "DNA sample" means any human biological specimen that is  
17 obtained or retained for the purpose of extracting and analyzing DNA to perform a  
18 genetic test; "DNA sample" includes DNA extracted from the specimen;

19 (8) "genetic characteristic" includes a gene, chromosome, or alteration  
20 of a gene or chromosome that may be tested to determine the existence or risk of a  
21 disease, disorder, trait, propensity, or syndrome, or to identify an individual or a blood  
22 relative; "genetic characteristic" does not include family history or a genetically  
23 transmitted characteristic whose existence or identity is determined other than through  
24 a genetic test;

25 (9) "genetic information" means information about an individual or the  
26 individual's blood relatives obtained from a genetic test;

27 (10) "genetic research" means research using DNA samples, genetic  
28 testing, or genetic information;

29 (11) "genetic test" means a test for determining the presence or  
30 absence of genetic characteristics in an individual or the individual's blood relatives,  
31 including tests of nucleic acids such as DNA, RNA, mitochondrial DNA,

1 chromosomes, or proteins in order to diagnose or determine a genetic characteristic;

2 (12) "obtain genetic information" means performing or getting the  
3 results of a genetic test;

4 (14) "research" means a systematic investigation, including research  
5 development, testing, and evaluation, designed to develop or contribute to generalized  
6 knowledge;

7 (15) "retain,"

8 (A) when used with regard to a DNA sample, means the act of  
9 storing the DNA sample;

10 (B) when used with regard to genetic information, means  
11 making a record of the genetic information.

12 \* **Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to  
13 read:

14 **INDIRECT COURT AMENDMENTS.** AS 18.13.050(e), added by sec. 1 of this Act,  
15 has the effect of amending Rule 82, Alaska Rules of Civil Procedure, and Rule 508, Alaska  
16 Rules of Appellate Procedure, relating to the awarding of attorney fees.