



12/15/2015

The Honorable Lesil McGuire
Alaska State Senate
State Capital Building, Rm.
Juneau, Alaska 99801

In Re: Amending the Alaska Genetic Privacy Act

Dear Senator McGuire:

Thank you for your interest and leadership in protecting the privacy of Alaskans' personal information within advancements in biotechnology. Your voice has been key on this issue since passage of the Alaska Genetic Privacy Act in 2004.

Please allow me to begin by introducing and describing our company, Family Tree DNA. We are a pioneering firm in the field of genetic genealogy, which involves the use of biotechnology to further genealogical research. An entire industry employing many people has developed, and many books were published since our inception in 2000. Genetic Genealogy is most commonly used in conjunction with traditional genealogical research tools, for example, to verify family relationships or fill gaps when traditional genealogical records are inadequate. In addition, a participant may also hope to find unknown, distant relatives who have also submitted a genetic sample to the same database.

Family Tree DNA sells a variety of DNA tests that are designed and focused on ancestry research. After a customer purchases a test and submits a DNA sample, Family Tree DNA conducts an analysis and privately shares the results with the customer via the customer's account on its website. In addition, Family Tree DNA lets customers share and/or compare their test results with others, with whom they have a relevant match, for free. To do so, the customer must first sign an optional release form. Thereafter, a customer can join an online genealogy project, most often a project based upon a common family surname.

Genetic genealogy differs from most other applications of biotechnology science in two ways: (1) rather than being used for medical purposes, genetic genealogy is used to establish ancestral relationships between people, and (2) rather than focusing on an individual, the core of genetic genealogy involves comparing certain genetic information from two or more individuals to determine whether there is a shared common ancestry.

We are requesting amendments to the Alaska Genetic Privacy Act to address the field of genetic genealogy. Based upon our review of the legislative history, it is apparent that Alaska lawmakers did not consider genetic genealogy when it enacted the Genetic Privacy Act. Given all the contributions this field has brought over the years to numerous families (including many adoptees), it is timely to consider these kinds of developments affected by the Alaska Genetic Privacy Act.

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Our goal in this exercise is to clarify that the Act does not apply to the field of genetic genealogy. Certain aspects of the Act already can be read to except genetic genealogy, but other aspects of the Act could be interpreted to include genetic genealogy.

If the Act is applied to the business and practice of genetic genealogy, the potential risk of doing business in Alaska in violation of the current law would be too high. This would prevent many of the benefits of genetic genealogy from being enjoyed by Alaskans. Rather than stifle this research opportunity for Alaskans and their families, we would respectfully recommend amendments to recognize genetic genealogy.

Genetic genealogy is not designed to reveal sensitive personal information; rather, it is designed to reveal ancestral information. The U.S. Food and Drug Administration does not regulate genetic genealogy, and has only become involved in the field when companies have claimed that their genetic tests can reveal medical information¹.

Anyone who conducts genealogical research by using genetic genealogy would rightfully expect for his and/or her test results to be shared and compared with others' test results. The purpose of keeping information private is inimical to the very function of genealogy to establish connections between individuals.

Under the Act, individual Alaskans are given the right to decide whether to take a DNA test and control the results of a DNA analysis. AS 18.13.010 provides:

[A] person may not collect a DNA sample from a person, perform a 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.

It makes little sense to impose the written informed consent requirements of the Act on the field of genetic genealogy. Informed consent is a medical concept, but genetic genealogy serves no medical purpose. In addition, because genealogy is inherently a comparative exercise, there is no need to require that Family Tree DNA's customers give a statutorily-required informed written consent for the obvious — i.e., the sharing and comparing of their genetic information. Applied to our internet business where customers voluntarily participate, the concept of informed written consent is vague and unnecessary.

There are also a few key relevant definitions under the Act:

"DNA analysis" means "DNA or genetic typing and testing to determine the presence or absence of genetic characteristics in an individual, including tests of nucleic acids or chromosomes in order to diagnose or identify a **genetic characteristic**." AS 18.13.100(2) (emphasis added). "DNA analysis" does not include "a routine physical measurement, a test for drugs, alcohol, cholesterol, or the human immunodeficiency virus, a chemical, blood, or urine analysis, or any other diagnostic test that is widely accepted and in use in clinical practice." *Id.*

¹ Please see *Direct-to-Consumer Genetic Testing and the Consequences to the Public Health: Hearing before the Subcomm. on Oversight & Investigations of the H. Comm. on Energy & Commerce*, 111 Cong. at 68, 75 (July 22, 2010), available at <http://www.gpo.gov/fdsys/pkg/CHRG-111hhr78125/pdf/CHRG-111hhr78125.pdf>

"Genetic characteristic" includes "a gene, chromosome, or alteration of a gene or chromosome 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." AS 18.13.100(3) (emphasis added). "Genetic characteristic" does not include "family history or a genetically transmitted characteristic whose existence or identity is determined other than through a genetic test." *Id.*

Genetic genealogy does not neatly fit within these definitions since we are primarily used to establish ancestral relationships between people rather than being used for medical purposes. Our core focus is comparing certain genetic information from two or more individuals to determine whether there is a shared common ancestry.

Hopefully this letter provides sufficient information to understand our situation and our goals. Please feel free to contact me should you have any questions or wish to discuss.

Sincerely,



Bennett Greenspan, Founder
Family Tree DNA