

STATE OF NEW YORK

8847

2017-2018 Regular Sessions

IN ASSEMBLY

December 22, 2017

Introduced by M. of A. OTIS -- read once and referred to the Committee on Consumer Affairs and Protection

AN ACT to amend the general business law, in relation to prohibiting the distribution of consumer's DNA profiles submitted to direct-to-consumer genetic testing companies

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

1 Section 1. The general business law is amended by adding a new section
2 399-dddd to read as follows:

3 § 399-dddd. Confidentiality of consumer DNA profile. 1. For purposes
4 of this section, the following terms shall have the following meanings:

5 (a) "Consumer DNA profile" means any DNA sample collected from a
6 consumer by a direct-to-consumer genetic testing company.

7 (b) "Direct-to-consumer genetic testing company" means any company
8 that provides genetic testing directly to consumers.

9 (c) "Consumer DNA database" means a direct-to-consumer genetic testing
10 company's electronic database containing DNA profiles generated from
11 consumer DNA samples.

12 2. No direct-to-consumer genetic testing company, or any other person,
13 firm, partnership, association or corporation, shall distribute to any
14 third party a consumer's DNA profile without first receiving the consent
15 of such consumer or removing all identifying information from such
16 consumer's DNA profile.

17 3. All direct-to-consumer genetic testing companies shall maintain a
18 privacy policy on their website and shall distribute either a written or
19 electronic copy of such privacy policy to every consumer that provides a
20 DNA sample to such companies. Such privacy policy shall include, but
21 shall not be limited to, a statement that any consumer DNA samples
22 collected will not be distributed to a third party, as provided in
23 subdivision two of this section.

EXPLANATION--Matter in italics (underscored) is new; matter in brackets
[-] is old law to be omitted.

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4. Any direct-to-consumer genetic testing company, or any person, firm, partnership, association or corporation who violates the provisions of this section shall be liable to a civil penalty of not more than one thousand dollars for a single violation and not more than ten thousand dollars for multiple violations resulting from a single act or incident. The second violation and any violation committed thereafter shall be punishable by a civil penalty of not more than five thousand dollars for a single violation and not more than fifty thousand dollars for multiple violations resulting from a single act or incident.

§ 2. This act shall take effect immediately.