



General Assembly

February Session, 2026

***Raised Bill No. 5128***

LCO No. 1124



Referred to Committee on GENERAL LAW

Introduced by:  
(GL)

***AN ACT CONCERNING DIRECT-TO-CONSUMER GENETIC TESTING.***

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. (NEW) (*Effective October 1, 2026*) As used in this section and  
2 sections 2 and 3 of this act:

3 (1) "Biological sample" (A) means any material that is derived from  
4 the human body and known to contain DNA, and (B) includes, but is  
5 not limited to, any human tissue, blood, urine or saliva;

6 (2) "Consumer" means any individual who is physically present in  
7 this state and a recipient, or a prospective recipient, of genetic testing;

8 (3) "De-identified data" means any data that cannot reasonably be  
9 used to infer information about, or otherwise be linked to, an identified  
10 or identifiable individual if the direct-to-consumer genetic testing  
11 company that possesses such data (A) takes administrative and  
12 technical measures to ensure that such data cannot be associated with  
13 an individual, (B) publicly commits to possess and use such data  
14 exclusively in de-identified form and not to attempt to reidentify such  
15 data, and (C) contractually obligates any recipient of such data to satisfy

16 the criteria set forth in subparagraphs (A) and (B) of this subdivision;

17 (4) "Direct-to-consumer genetic testing company" or "company"  
18 means any person doing business in this state who, in the ordinary  
19 course of such business, (A) offers genetic testing directly to a consumer,  
20 or (B) collects, uses or analyzes genetic data that a consumer has  
21 provided to such person;

22 (5) "DNA" means deoxyribonucleic acid;

23 (6) "Express consent" means an affirmative response by a consumer  
24 to a clear, meaningful and prominent notice regarding the collection,  
25 use, retention or disclosure of the consumer's genetic data for a specific  
26 purpose;

27 (7) "Genetic data" (A) means any data, regardless of format,  
28 concerning an individual's genetic characteristics, (B) includes, but is  
29 not limited to, (i) any raw sequence data that result from sequencing all,  
30 or any portion of, an individual's DNA, (ii) any genotypic or phenotypic  
31 information that is obtained by analyzing an individual's raw sequence  
32 data, and (iii) any information that (I) concerns a condition affecting an  
33 individual's health, (II) the individual reports to a direct-to-consumer  
34 genetic testing company, and (III) the direct-to-consumer genetic testing  
35 company analyzes in connection with the individual's raw sequence  
36 data and uses for scientific research or product development, and (C)  
37 does not include de-identified data;

38 (8) "Genetic testing" means (A) any laboratory test performed on an  
39 individual's complete DNA sequence, or one or more of an individual's  
40 DNA regions, chromosomes, genes or gene products, for purposes of  
41 determining the presence or absence of any genetic characteristic, and  
42 (B) any interpretation of an individual's genetic data; and

43 (9) "Person" means any individual, association, corporation, limited  
44 liability company, partnership, trust or other legal entity.

45       Sec. 2. (NEW) (*Effective October 1, 2026*) A consumer shall have a  
46 property right in, and shall retain the right to exercise exclusive control  
47 over, any biological sample that is derived from the consumer's body  
48 and provided to, or used by, a direct-to-consumer genetic testing  
49 company, as well as the results of any genetic testing conducted on the  
50 consumer's DNA by a direct-to-consumer genetic testing company.  
51 Such right to exercise exclusive control includes, but is not limited to,  
52 the right to exercise exclusive control over the collection, use, retention,  
53 maintenance, disclosure or destruction of such biological sample and  
54 results.

55       Sec. 3. (NEW) (*Effective October 1, 2026*) (a) A direct-to-consumer  
56 genetic testing company shall:

57       (1) At all times transact its business and conduct its affairs in a  
58 manner that is consistent with a consumer's rights under section 2 of this  
59 act;

60       (2) Prior to accepting any biological sample, genetic data or payment  
61 from a consumer, disclose to the consumer the company's policies and  
62 procedures concerning the collection, use and disclosure of genetic data;

63       (3) Display, in a prominent and publicly accessible location on the  
64 company's Internet web site, a privacy notice disclosing such company's  
65 policies and procedures concerning the collection, use, access,  
66 disclosure, transfer, security, retention and deletion of a consumer's  
67 data and the consumer's consent thereto;

68       (4) Prior to collecting, using or disclosing a consumer's genetic data,  
69 obtain the consumer's express consent for such collection, use or  
70 disclosure after disclosing to such consumer (A) the company's policies  
71 and procedures concerning use of the genetic data such company  
72 collects from consumers, (B) the identity of each person who may access  
73 the results of genetic testing performed by the company, including, but  
74 not limited to, any vendor or service provider for such company who  
75 may access such results, and (C) the manner in which the company may

76 disclose such consumer's genetic data;

77 (5) In addition to the express consent required under subdivision (4)  
78 of this subsection, separately obtain a consumer's express consent to (A)  
79 disclose or transfer the consumer's genetic data to any person other than  
80 a vendor or service provider for the company prior to disclosing or  
81 transferring such genetic data to such person, (B) use the consumer's  
82 genetic data for any purpose other than the primary purpose for which  
83 the company offered genetic testing directly to such consumer prior to  
84 using such genetic data for such other purpose, or (C) retain the  
85 consumer's biological sample for any period following completion of  
86 the genetic testing for which such consumer provided such biological  
87 sample prior to retaining such biological sample for such period;

88 (6) Obtain informed consent from a consumer in accordance with the  
89 federal policy for the protection of human subjects under 45 CFR 46, as  
90 amended from time to time, for any disclosure or transfer of the  
91 consumer's genetic data to a third party for research purposes or  
92 research conducted under the control of the company for purposes of  
93 publication or generalizable knowledge;

94 (7) Not disclose the results of any genetic testing performed on a  
95 consumer's DNA to any person other than the consumer, unless (A) the  
96 company has obtained such consumer's express consent to such  
97 disclosure, or (B) such disclosure is made to a person acting pursuant to  
98 a court order, warrant or subpoena;

99 (8) Not disclose a consumer's genetic data to (A) the consumer's  
100 employer, (B) any person who, in the ordinary course of business, (i)  
101 offers health insurance, life insurance or long-term care insurance  
102 coverage in this state or any other state, or (ii) provides information or  
103 data to any insurer, as defined in section 38a-1 of the general statutes,  
104 health care center, as defined in section 38a-175 of the general statutes,  
105 or fraternal benefit society, as described in section 38a-595 of the general  
106 statutes, for purposes of underwriting or rating of risks, or (C) any third

107 party which the company knows, or reasonably should know, intends  
108 to use such genetic data for purposes of marketing, including, but not  
109 limited to, targeted advertising;

110 (9) Implement reasonable security measures to protect a consumer's  
111 biological sample or genetic data from any unauthorized access,  
112 destruction, use, modification or disclosure; and

113 (10) Implement a process for a consumer to (A) access the consumer's  
114 genetic data from the company, (B) require the company to delete the  
115 consumer's genetic data, (C) require the company to destroy, and  
116 confirm that such company has destroyed, the consumer's biological  
117 sample, and (D) revoke the consumer's consent for (i) the company to  
118 use such consumer's genetic data for research purposes, or (ii) any third  
119 party to which the company has provided such consumer's genetic data  
120 to use such genetic data for research purposes.

121 (b) Any violation of subsection (a) of this section shall be deemed an  
122 unfair or deceptive trade practice under subsection (a) of section 42-110b  
123 of the general statutes.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>October 1, 2026</i>	New section
Sec. 2	<i>October 1, 2026</i>	New section
Sec. 3	<i>October 1, 2026</i>	New section

**Statement of Purpose:**

To (1) provide that a consumer has a property right in, and retains the right to exercise exclusive control over, (A) any biological sample that is derived from the consumer's body and provided to, or used by, a direct-to-consumer genetic testing company, and (B) the results of any genetic testing conducted on the consumer's DNA by a direct-to-consumer genetic testing company, and (2) specify various duties and limitations applicable to direct-to-consumer genetic testing companies.

*[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]*