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HOUSE OF REPRESENTATIVES
152nd GENERAL ASSEMBLY

HOUSE SUBSTITUTE NO. 1
FOR
HOUSE BILL NO. 286

AN ACT TO AMEND TITLE 18 OF THE DELAWARE CODE RELATING TO GENETICS BASED
DISCRIMINATION.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

1 Section 1. Amend § 2317, Title 18 of the Delaware Code by making deletions as shown by strike through and
2 insertions as shown by underline as follows:

3 § 2317. Genetics based ~~discrimination~~. discrimination prohibited; health insurance.

4 (a) For purposes of this section:

5 (1) “Genetic characteristic” means any inherited gene or chromosome, or alteration thereof, that is scientifically or
6 medically believed to predispose an individual to a disease, disorder, or syndrome, or to be associated with a statistically
7 significant increased risk of development of a disease, disorder, or syndrome.

8 (2) “Genetic information” means information about inherited genes or chromosomes, and of alterations thereof,
9 whether obtained from an individual or family member, that is scientifically or medically believed to predispose an
10 individual to disease, disorder, or syndrome, or believed to be associated with a statistically significant increased risk of
11 development of a disease, disorder, or syndrome. “Genetic information” includes information regarding carrier status,
12 information regarding an increased likelihood of future disease or increased sensitivity to any substance, information
13 derived from laboratory tests that identify mutations in specific genes or chromosomes, requests for genetic services or
14 counseling, tests of gene products, and direct analysis of genes or chromosomes.

15 (3) “Genetic test” means a test for determining the presence or absence of an inherited genetic characteristic in an
16 individual, including tests of nucleic acids such as DNA, RNA and mitochondrial DNA, chromosomes or proteins in order
17 to identify a predisposing genetic characteristic associated with disease, disorder, or syndrome.

18 (4) “Insurance” means ~~health coverage~~ “health insurance” as defined in § 3602(11) of this title ~~or in regulations~~
19 ~~promulgated by the Insurance Commissioner, not including~~ title. “Insurance” does not include disability insurance or long-
20 term care insurance.

21 Section 2. Amend Chapter 23, Title 18 of the Delaware Code by making deletions as shown by strike through and
22 insertions as shown by underline as follows:

23 § 2317A. Genetics based discrimination prohibited; life insurance and annuities.

24 (a) For purposes of this section:

25 (1) “Direct-to-consumer genetic testing” means any of the following:

26 a. A consumer-initiated genetic testing product or service offered directly to a consumer.

27 b. The collection, use, or analysis of genetic data that is collected or derived from a direct-to-consumer
28 genetic testing product or service and is directly provided by a consumer.

29 (2) “Life insurance” means contracts for life insurance and annuities under Chapter 29, Chapter 31, or Chapter
30 32 of this title.

31 (3) The following terms mean as defined in § 2317 of this title:

32 a. “Genetic characteristic”.

33 b. “Genetic information”.

34 c. “Genetic test”.

35 (b) Except as provided under subsection (c) of this section, a person engaged in the business of life insurance may
36 not do any of the following solely based on any genetic characteristic, genetic information, or the result of any genetic test:

37 (1) Deny, refuse to issue, refuse to renew, refuse to reissue, cancel, or otherwise terminate an insurance policy
38 or restrict coverage.

39 (2) Add any surcharge or rating factor to a premium of an insurance policy.

40 (3) Otherwise discriminate in the offering, issuance, cancellation, amount of coverage, price, payment of
41 claims, or any other condition of an insurance policy without additional actuarial justification.

42 (c) Subsection (b) of this section does not apply to any genetic characteristic, genetic information, or the result of
43 any genetic test that is in any of the following:

44 (1) An individual’s medical record or pertinent family history.

45 (2) An individual’s application for life insurance.

46 (d) A person engaged in the business of life insurance may not do any of the following:

47 (1)a. Require or request that an individual or a member of the individual’s family take a genetic test.

- 48 b. Take into consideration the refusal by an individual to take a genetic test.
- 49 (2)a. Require that an individual provide genetic information received from an entity providing direct-to-
- 50 consumer genetic testing.
- 51 b. Require that an individual provide written consent for an entity providing direct-to-consumer genetic
- 52 testing to share information about the individual.
- 53 c. Take into consideration the refusal by an individual to provide genetic information or written consent
- 54 under paragraphs (d)(2)a. or (d)(2)b. of this section.
- 55 (e) An entity providing direct-to-consumer genetic testing may not share any information with a person engaged in
- 56 the business of life insurance without the written consent of the individual as required under § 1202 of Title 16.
- 57 Section 3. This Act is known as "The Ericka Byler Act".

SYNOPSIS

Like House Bill No. 286, House Substitute No. 1 for House Bill No. 286 prohibits discrimination in life insurance based on genetic characteristics, genetic information, or the result of any genetic test.

House Substitute No. 1 for House Bill No. 286 differs from House Bill No. 286 as follows:

1. Provides a definition of "direct-to-consumer genetic testing".
2. Allows the use of any genetic information that is in an individual's medical record or application for life insurance.
3. Allows a person engaged in the business of life insurance to request that an individual share genetic information from a direct-to-consumer genetic testing or to request that an individual provide written consent for entity to provide that information.
4. Allows an entity that provides direct-to-consumer genetic testing to share information with a person engaged in the business of life insurance but only with the written consent of the individual.
5. Clarifies that a person engaged in the business of life insurance may not do any of the following:
 - a. Require that an individual take a genetic test.
 - b. Require that an individual provide genetic information received from an entity providing direct-to-consumer genetic testing or provide written consent for the entity to provide that information.
 - c. Take into consideration the refusal by an individual to take a genetic test, provide genetic information received from direct-to-consumer genetic testing, or provide written consent to share information from direct-to-consumer genetic testing.

Like HB 286, HS 1 for HB 286 also does all of the following:

1. Makes corresponding corrections to § 2317 of Title 18 by revising the heading for clarity and the definition of "insurance" to conform with the terms and definitions used in Title 18.
2. Is known as "The Ericka Byler Act".