Date of Hearing: April 15, 2026

ASSEMBLY COMMITTEE ON INSURANCE
Lisa Calderon, Chair
AB 1798 (Wilson) – As Amended April 8, 2026

SUBJECT: Genetic testing for life and disability insurance

SUMMARY: Prohibits life and non-health disability insurers from using genetic information or biomarker results for any insurance purpose other than paying benefits or for a therapeutic purpose. Specifically, **this bill**:

1) Prohibits an insurance institution, agent, or insurance-support organization from preparing or requesting an investigative consumer report that seeks an individual's full genome or genetic information originally requested by the individual or obtained by the individual from a direct-to-consumer (DTC) genetic testing company.

2) Prohibits an insurance institution, agent, or insurance-support organization from seeking information in connection with an insurance transaction concerning an individual's full genome or genetic information originally requested by the individual or obtained by the individual from a DTC genetic testing company.

3) Prohibits an insurance institution or agent from basing an adverse underwriting decision in whole or in part on an individual's full genome or genetic information originally requested by the individual or obtained by the individual from a DTC genetic testing company.

4) Clarifies that the purpose of Insurance (Ins.) Code provisions governing underwriting based on genetic characteristics includes, among other things, to expand prohibitions against the use of genetic information and genetic testing by insurers to include entities that issue policies of life and disability insurance.

5) Prohibits a life or disability insurer from cancelling, limiting, or denying coverage, establishing differentials in premium rates, conditions, or terms, or making an adverse underwriting decision based on a test for the presence of a genetic characteristic.

6) Prohibits a life or disability insurer from requiring, requesting, or soliciting genetic information, using genetic test results, or considering a person's decisions or actions relating to genetic testing in any manner for an insurance purpose, except as necessary for the payment of benefits or for a therapeutic purpose.

7) Prohibits a life or disability insurer from requiring a person to undergo a test of the person's genetic characteristics or undergo biomarker testing to determine eligibility or insurability or for other insurance purposes.

8) Prohibits a life or disability insurer from asking a person if they or any member of their family have taken a genetic test, or asking about the result of a genetic test.

9) Clarifies that the provisions of the bill do not prevent a life or disability insurer from accessing an individual's medical record as part of an application for insurance, provided the insurer does not directly or indirectly consider or use genetic information or genetic test

results of the individual or the individual's family, whether obtained from medical records or other sources, in underwriting or rating decisions.

10) Authorizes the Insurance Commissioner ("commissioner") to promulgate reasonable rules and regulations and amendments and additions as necessary to administer the provisions of the bill.

11) Clarifies that an insurer does not violate the bill by receiving genetic information or the results of a genetic test, provided it does not directly or indirectly use the information or results in its underwriting or rating, and does not disclose the genetic information or genetic test in a way that violates the bill's provisions.

12) Increases the penalty for a person who either uses genetic information or genetic characteristics in a manner inconsistent with the bill's provisions, or negligently discloses genetic information or characteristics, to any third party in a manner that identifies the person to whom the test results apply from a maximum of $1,000 per violation plus court costs to a maximum of $5,000, to be paid to the subject of the test.

13) Specifies that a person who either knowingly, or with such frequency as to indicate a general business practice, commits an act specified in 12), above, shall be assessed a civil penalty in an amount not less than $1,000 and no more than $10,000 per violation.

14) In addition to the penalties specified in 12) and 13), above, specifies that any life or disability insurer who violates the bill's provisions is liable for administrative penalties of not less than $1,500 and not more than $2,500 for the first violation, and not less than $2,500 or more than $5,000 for each subsequent violation.

15) Provides that any life or disability insurer that violates the bill's provisions with a frequency that indicates a general business practice or commits a knowing violation is liable for administrative penalties of not less than $15,000 and not more than $100,000 for each violation.

16) Specifies that an act or omission that is inadvertent and results in incorrect premium rates being charged to more than one insured shall be a single violation for the purposes of the section, and provides the commissioner with the discretion to establish what constitutes an "act."

17) Provides the commissioner with the authority to assess penalties in accordance with the bill's provisions, in addition to any other fine, penalty, or remedy permitted by law, against life and disability insurers.

18) Defines "genetic information" for the purposes of the bill to mean information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder, or syndrome, or are associated with a statistically increased risk of developing a disease, disorder, or syndrome, which is asymptomatic at the time of testing.

19) Defines "biomarker" to mean a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacological

responses to a specific therapeutic intervention, and defines "biomarker testing" to mean the analysis of an individual's tissue, blood, or other biospecimen for the presence of a biomarker, for the purposes of the bill's provisions.

EXISTING LAW:

1) Prohibits discrimination on the basis of genetic information under the Unruh Civil Rights Act and the Fair Employment and Housing Act (FEHA). (Civil (Civ.) Code Sec. 51; Government Code Sec. 12920 et seq.)

2) Prohibits, pursuant to federal law under the Genetic Information and Nondiscrimination Act (GINA), discrimination based on genetic information in group health plan coverage and employment. (Pub. Law 110-233.)

3) Subjects any person who improperly discloses genetic test results contained in a health care service plan applicant or enrollee's medical records, or pursuant to a genetic test requested by an insurer, to civil and criminal penalties. (Civ. Code Sec. 56.17; Ins. Code Sec. 10149.1.)

4) Prohibits a DTC genetic testing company from disclosing a consumer's genetic data to any entity that is responsible for administering or making decisions regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment, or to any entity that provides advice to an entity that is responsible for performing those functions, except as specified. (Civ. Code Sec. 56.181(f)(1))

5) Prohibits a life or disability insurer from requiring a test for the presence of a genetic characteristic for the purpose of determining insurability other than for those policies that are contingent on review or testing for other diseases or medical conditions. (Ins. Code Sec. 10148(a))

6) Provides that, if a test is permissible and required pursuant to 6), the test be done in accordance with specified informed consent and privacy protection provisions, and the cost of the test be paid by the insurer. (Ins. Code Sec. 10148(a) & (d))

7) Prohibits discrimination made in the fees or commissions of agents or brokers writing or renewing a life or disability income policy on the basis of a test of that person's genetic characteristics. (Ins. Code Sec. 10148(g))

8) Prohibits life and disability insurers from failing or refusing to accept an application for insurance, from failing to issue insurance to an applicant, and from issuing insurance under conditions less favorable to the insured than in other comparable cases, except for reasons applicable alike to persons of every race, color, religion, sex, gender, gender identity, gender expression, national origin, ancestry, or sexual orientation; and prohibits considering race, color, religion, national origin, ancestry, and sexual orientation from, of itself, constituting a condition or risk for which a higher rate, premium, or charge may be required of the insured for that insurance, except as specified. (Ins. Code Sec. 10140(a))

9) Prohibits life and disability insurers from refusing to issue/sell or renew a policy, or from requiring beneficiaries to accept less than the full sum of the policy, solely because the person to be insured carries a gene which may, under some circumstances, be associated with

disability in that person's offspring, but which causes no adverse effects to the carrier. (Ins. Code Sec. 10143)

10) Defines "genetic characteristics" to mean any scientifically or medically identifiable gene or chromosome, or alteration thereof, that is known to be a cause of a disease or disorder, or that is determined to be associated with a statistically increased risk of development of a disease or disorder, and that is presently not associated with any symptoms of any disease or disorder. (Ins. Code Sec. 10147(b))

FISCAL EFFECT: Unknown.

COMMENTS:

1) *Purpose.* According to the author:

> California has a responsibility to lead when it comes to protecting patients and advancing health equity. As genetic testing and biomarker screening become more widely used, we must ensure that these innovations don't deepen existing disparities or create new barriers to coverage. AB 1798 ensures that Californians are not penalized for taking proactive steps to understand their health. Genetic testing and biomarker screening should lead to better health, not higher premiums, reduced benefits, or denial of coverage.

This bill is sponsored by Insurance Commissioner Ricardo Lara.

2) *Life insurance and non-health disability insurance.* Life insurance is a type of insurance product that entitles one's beneficiaries to a financial benefit upon death. Life insurance can either be "term" life insurance or "permanent" life insurance. Term life insurance covers the individual for a specified period. Following that period, assuming the individual is still alive, the individual ceases to pay premiums, and a death benefit is no longer available. Permanent life insurance, on the other hand, is typically more expensive than term life insurance, and provides a guaranteed death benefit provided the individual continues to pay premiums. Unlike homeowners' insurance, auto insurance, and health insurance, life insurance is an entirely voluntary product.

Disability insurance provides a source of income if an individual can no longer work due to a disability. Private disability insurance can be used to supplement state disability insurance, which does not provide complete income replacement, especially for high earners. Like life insurance, private disability insurance is also entirely voluntary.

3) *Genetic nondiscrimination in insurance.* In 2008, Congress passed the Genetic Information Nondiscrimination Act (GINA), which prohibits discrimination based on genetic information in group health plan coverage and employment, but GINA does not address discrimination based on genetic information in life and non-health disability insurance. (Pub. Law 110-233)

The ALS Association argues in support of the bill:

> The Genetic Information Nondiscrimination Act (GINA) was an important first step, but it leaves individuals vulnerable to discrimination in life, disability, and long-term care insurance. The American Medical Association has concluded that these gaps negatively

> impact clinical care and that stronger protections are necessary to support patient trust and engagement in genomic medicine.
>
> Research consistently shows that fear of genetic discrimination is already harming patient care and slowing scientific progress. […] A randomized study found that 28% of individuals declined genomic research due to fear of insurance discrimination. At a population level, concern is widespread: over 60% of adults report worry that genetic test results could impact their access to life, disability, or long-term care insurance. [Citation]

In California, the Unruh Civil Rights Act prohibits discrimination on the basis of genetic information with respect to "the full and equal accommodations, advantages, facilities, privileges, or services in all business establishments of every kind whatsoever" (Civ. Code Sec. 51(a)), and the Fair Employment and Housing Act (FEHA) prohibits genetic discrimination in the housing and employment contexts. (Gov. Code Sec. 12921)

In the insurance context, California law prohibits life and disability insurers from refusing to issue/sell or renew a policy, or from requiring beneficiaries to accept less than the full sum of the policy, solely because the person to be insured carries a gene "which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects to the carrier." (Ins. Code Sec. 10143) That provision specifically identifies genes including, but not limited to, Tay-Sachs trait, sickle cell trait, thalassemia trait, and X-linked hemophilia A. Section 10146, *et seq.*, of the Insurance Code also lays out specific criteria controlling the practice of underwriting on the basis of genetic characteristics for the life and disability insurance industries, with the following purpose:

> The purposes of this article are to establish standards regarding unfair discrimination among individuals of the same class in the underwriting of life or disability income insurance on the basis of tests of a person's genetic characteristics; to establish minimum standards for determining insurability which are sufficiently reliable to be used for life and disability income insurance risk classification and underwriting purposes; to require the maintenance of strict confidentiality of personal information obtained through a test of a person's genetic characteristics; and to require informed consent before insurers underwrite on the basis of a test of a person's genetic characteristics. […] (Ins. Code Sec. 10146)

Consistent with these objectives, Section 10148 prohibits a life or disability insurer from requiring a test for the presence of a genetic characteristic for the purpose of determining insurability other than for policies that are contingent on review or testing for other diseases or medical conditions, and requires informed consent and specified privacy protections if such a test is conducted. Section 10148 further requires that any such test be paid for the by requiring insurer, and prohibits a policy from limiting benefits otherwise payable if loss is caused or contributed to by the presence or absence of genetic characteristics, except to the extent that coverage is limited for loss caused or contributed to by other medical conditions presenting an increased degree of risk. Section 10148 also prohibits discrimination in the fees or commissions of agents or brokers writing or renewing a life or disability income policy on the basis of a test of that person's genetic characteristics, prescribes penalties for the unauthorized disclosure of identifiable genetic information. These protections do not go as far as prohibiting consideration of genetic information in life and disability insurance underwriting, resulting in less expansive protections for genetic information in the life and disability insurance space than in the health insurance space pursuant to GINA.

In 2021, Governor Newsom signed into law SB 41 (Umberg, Ch. 596, Stats. 2021), also known as the Genetic Information Privacy Act (GIPA), which provided several privacy and consumer protections for genetic information collected through DTC testing. Among these protections was a prohibition on DTC genetic testing companies disclosing a consumer's genetic data "to any entity responsible for administering or making decisions regarding health insurance, life insurance, long-term care insurance, disability insurance, or employment, or to any entity that provides advice to an entity that is responsible for performing these functions." (Civ. Code Sec. 56.181(f)(1))

As the California Life Sciences Association explains in support of the bill:

> Under current law, life and non-health disability insurers may obtain medical records that include genetic or biomarker information – even when such testing was not requested by the insurer. In these cases, existing informed consent and privacy protections may not apply. This creates a real risk that individuals who pursue genetic testing or biomarker screening in good faith could face higher premiums, reduced benefits, or denial of coverage based on information they voluntarily obtained to improve their health. As a result, Californians may be discouraged from accessing clinically valuable tools that are foundational to modern, preventative care.

4) *Asymmetry of information and adverse selection.* For all insurance products, the premiums set by the insurer must accurately reflect the risk assumed in order to ensure the product remains accessible and the market remains stable. In the life and disability insurance space, this means insurers comprehensively assess the applicant's medical information, family history, lifestyle choices such as smoking, alcohol consumption, and drug use, occupation, hobbies, and driving record, among other things. The result is that applicants who present higher morbidity or disability risk are offered higher premiums, or in some cases denied coverage entirely, while lower risk applicants can receive lower premiums. This means that, regardless of risk category, the value of the insurance to the applicant should remain relatively equal – if risk is high, the potential benefit of having insurance is high, but so is cost, while if risk is low, the potential benefit of having insurance is accordingly lower, but cost is also lower. This ideally maintains a relatively balanced consumer base that generally reflects the risk across the population.

   If, however, the applicant has access to material information to which the insurer does not, this balance can be disrupted. If an applicant knows they present significant risk but the insurer cannot adequately account for this, the premium would not reflect the risk incurred. This presents two problems if it is commonplace: 1) the insurer may not take in the requisite revenue to cover the frequency of necessary payouts; and 2) the value of the insurance to a high-risk individual increases, incentivizing more high-risk individuals to purchase the product. As the unanticipated costs compound, the average risk of the insured population increases, meaning premiums must increase for all policyholders, including those who are low risk. This reduces the value of the product for lower risk individuals who may consequently be less likely to purchase the product, creating a feedback loop that can further increase the high-risk segment of the insured population. This can lead to an increase in premiums for all those seeking life insurance, and at worst, the result could destabilize the market. This is known as adverse selection.

A coalition of trade organizations representing the life insurance industry, consisting of the American Council of Life Insurers (ACLI), Association of California Life and Health Insurance Companies (ACLHIC), and National Association of Insurance and Financial Advisors – California (NAIFA), argues in opposition to the bill:

> At its core, life insurance works because both parties share the same material information at the time the policy is issued. Life insurance is a long-term promise. Once a policy is issued, an insurer cannot raise the premium, cannot cancel coverage so long as premiums are paid, and has only one chance to underwrite the risk.
>
> That system functions because underwriting is based on complete and accurate information from both the applicant and the insurer. When both sides have the same material medical information, premiums reflect the true level of risk. […]
>
> If AB 1798 allows applicants to withhold material medical information, it undermines the balanced symmetry of information these long-term contracts depend on and will force insurers to set premiums without a full and accurate picture of the risk they are insuring.

That said, most insurance markets tolerate some information asymmetry to avoid unfair discrimination. For instance, Section 10140(a) of the Insurance Code prohibits life and disability insurers from failing or refusing to accept an application for insurance, from failing to issue insurance to an applicant, and from issuing insurance under conditions less favorable to the insured than in other comparable cases, except for reasons applicable alike to persons of every race, color, religion, sex, gender, gender identity, gender expression, national origin, ancestry, or sexual orientation. The same provision also prohibits considering race, color, religion, national origin, ancestry, and sexual orientation from, of itself, constituting a condition or risk for which a higher rate, premium, or charge may be required of the insured for that insurance. These factors may very well correlate with increased or decreased risk of mortality in certain circumstances, but costs associated with that variance are instead absorbed by the insured population as a whole, rather than by the higher-risk individuals, in the form of higher premiums.

Notably, this antidiscrimination provision does permit consideration of sex of an individual when establishing premium, price, or charge differentials if the differential is based on "objective, valid, and up-to-date statistical and actuarial data or sound underwriting practices […]."

Still, with this in mind, whether it is appropriate to foreclose the use of genetic information in underwriting depends on whether one considers genetic information to be a potential factor for unfair discrimination like race, or a necessary factor in evaluating risk like medical history.

Insurance Commissioner Ricardo Lara, who sponsors the bill, argues:

> Genetic information differs from traditional underwriting factors because it most often suggests a remote chance of future diseases rather than a reasonably anticipated risk. Medical experts emphasize that genetic tests cannot reliably predict if or when a disease

> will occur and should not be used to penalize healthy individuals. […] The [American Medical Association] notes that discrimination based on genetic information is particularly problematic because it targets individuals who have not manifested any symptoms, disease or disorder based solely on the possibility one might manifest in the future.

The associations between genes and diseases or disorders are, in the overwhelming majority of circumstances, correlational rather than causal. In other words, the actual nature of the relationship between the gene and the disease or disorder is unclear, but populations with that genotype are more or less likely to develop that disease or disorder. As such, the possibility exists that the relationship is actually mediated by a third variable which is prohibited from consideration under existing law. For example, a genotype more common in a particular race may also correlate with an increased probability of developing a disease or disorder, but the gene is not causally related to the disorder and the correlation is instead due to other, non-genetic factors disproportionately impacting that racial group. In these cases, the gene would inadvertently serve as a proxy for underwriting determinations on the basis of a prohibited characteristic. Genetic information is also inherently rooted in ancestry, which is included as a prohibited characteristic under Section 10140(a). It is unclear how predictive uses of genetic information can comply with that prohibition.

5) *Laws governing use of genetic information in life insurance abroad.* Several countries have implemented full or partial bans on the use of genetic information for underwriting life and disability insurance. It should be noted that one-to-one comparisons between these regulatory regimes and the statutory scheme proposed in this bill are not necessarily appropriate, considering differences between countries and cultures. For instance, several of these countries provide publicly-funded universal healthcare, which may impact the likelihood of genetic predispositions resulting in adverse health outcomes long-term. Still, life insurance remains a viable product in all of these countries, despite their various regulations.

France

France prohibits the use of genetic information for any purpose other than medical and scientific endeavors. Using genetic information for any other purpose, including in life or disability insurance underwriting, is punishable with one year of imprisonment and a €15,000 fine. In other words, France maintains a complete ban on the use of genetic information in life and disability insurance underwriting.

Switzerland

Switzerland's Federal Act on Human Genetic Testing prohibits genetic discrimination in life and disability insurance. The Act requires a life or disability insurer to obtain the individual's consent to perform a genetic test, and prohibits the use of the results of a genetic test in underwriting a life insurance policy under CHF400,000 (approx. $500,000 USD) or a disability policy under CHF40,000 annually (approx. $50,000 USD). Switzerland therefore sets a financial threshold for life and disability insurance policies above which the use of genetic information is permissible.

Canada

In 2017, Canada enacted the Genetic Non-Discrimination Act, which prohibits requiring genetic testing or requiring disclosure of genetic test results as a contractual condition of supplying goods or services. All forms of insurance are subject to this law, including life and disability insurance. The law also prohibits insurers from using genetic test results even if they are made available to them. This means that Canada likewise maintains a complete ban on the use of genetic information in life and disability insurance underwriting, punishable by a fine of up to CAD$1,000,000 or imprisonment of up to five years.

Australia

In July 2019, the Financial Services Council of Australia established a moratorium on the use of genetic test results for insurance. The moratorium specified that Australians do not need to disclose adverse genetic test results for policies up to AUD$500,000 for death and permanent disability, AUD$200,000 for trauma, and AUD$4,000 per month for income protection (equivalent to approx. $350,000, $150,000, and $3,000 USD per month, respectively).

However, earlier this month (April 2026), the Australian Parliament passed the Genetic Testing Protections in Life Insurance Bill, which prohibits life insurers from requiring disclosure of genetic test results for policies of any size. The Bill does not, however, prevent individuals from volunteering genetic test results with written consent, and allows use of the volunteered results in underwriting only if it would not adversely impact the insurance offer or policy terms.

United Kingdom

The UK adopted a non-legislative approach to this issue by negotiating and adopting the Code on Genetic Testing and Insurance in coordination with the Association of British Insurers (ABI). This arrangement relies on the continued commitment to the Code from the ABI in exchange for the government refraining from introducing more prohibitive legislation pertaining to the use of genetic information in insurance underwriting.

Under the Code, ABI is prohibited from requiring the disclosure of predictive genetic test results unless independent experts provide approval by establishing that the test applies only to a single-gene disorder with late-onset and a high probability of being expressed (i.e. high penetrance). Thus far, only tests for Huntington's disease, which in some circumstances has 100% penetrance, have been approved. Otherwise, to require an individual's predictive genetic information, the individual must be seeking coverage for life, critical illness, or income protections above a financial limit of £500,000, £300,000, and £30,000 annually, respectively (equivalent to ~ $670,000, $400,000, and $40,000 USD annually, respectively).

Singapore

In 2021, Singapore's Ministry of Health, in coordination with the Life Insurance Association, established the Moratorium on Genetic Testing and Insurance, which prohibits the use of genetic test results in insurance underwriting, except under specified circumstances. The Moratorium was then amended and re-signed in 2025. Under the Moratorium, life insurers may not require or pressure an individual to take a genetic test if the individual has not taken one, and may not request and/or use previously obtained genetic test results in insurance underwriting unless:

- The test was a *diagnostic* genetic test, meaning it "confirms or rules out a diagnosis based on existing symptoms, signs or abnormal non-genetic test results which indicate that the condition in question may be present"; or

- The test was a *predictive* genetic test, meaning it "predicts a future risk of disease in individuals without symptoms or signs of a genetic disorder," AND the predictive test is one of a set of Approved Predictive Genetic Tests, AND the sum of payouts under the insurance is above the Approved Financial Limit. For life insurance, this applies only to tests for Huntington's disease and to policies above the higher of S$2,000,000 (approx. $1,500,000 USD) or the amount of the sum assured in life insurance in the 99th percentile of all life insurance in Singapore at the time the insurance is written.

The Moratorium also prohibits the use of genetic information derived from DTC tests for insurance purposes under any circumstances. According to the Ministry of Health, "The Moratorium aims to give individuals the assurance to undergo clinical genetic testing for medical care and to participate in [precision medicine] research, by protecting genetic test results from use by insurers in underwriting."

6) *Florida and Louisiana approaches*. In 2020, the Florida legislature passed HB 1189 (Ch. 2020-159), which, in the absence of a diagnosis of a condition related to genetic information, prohibits health insurers, life insurers, and long-term care insurers from canceling, limiting, or denying coverage, or establishing differentials in premium rates, based on genetic information. HB 1189 also prohibits these insurers from requiring or soliciting genetic information, using genetic test results, or considering a person's decisions or action relating to genetic testing in any manner for any insurance purpose. In the six years since HB 1189 has gone into effect, Florida has not seen a significant retreat of the life insurance industry, nor have premiums increased disproportionately relative to the national average. Life insurance trade groups who oppose this bill contend that because life insurance typically does not pay out for many years after a policy is purchased, the full effects of HB 1189 are not yet reflected in the market.

In 2021, the Louisiana legislature passed HB 703 (Act No. 242), which expands provisions prohibiting the use of genetic testing for health insurance and underwriting purposes to life and long-term care insurance policies. Specifically, HB 703 prohibits insurers from canceling or refusing to renew an existing policy based on the fact that an individual or a family member requested or received genetic services or participated in genetic research. HB 703 also prohibits an insurer from purchasing genetic information about an individual without the individual's consent. In contrast to Florida's HB 1189, however, HB 703 permits the consideration of genetic information contained in an applicant's medical record "if the information is relevant to a potential medical condition that impacts mortality or morbidity, and consideration of the genetic information is based on sound actuarial principles or reasonably expected experience. In this way, Louisiana's HB 703 is far more permissive with respect to the use of genetic information in insurance underwriting than Florida's HB 1189.

Though these divergent approaches to protecting genetic information in the life and disability insurance industry have already had over five years to produce market impacts, on the scale of life insurance, five years is a relatively short period. It remains to be seen whether material market impacts eventually emerge in either of these states as a consequence of adoption of these policies.

7) *Committee amendments.* Given the sensitivity of this issue, it is essential that the Legislature strike an appropriate balance between protecting genetic privacy, encouraging proactive genetic screening and participation in genetic studies, and preventing discrimination on the one hand, and maintaining the stability of the life insurance market on the other. While the bill in print seems likely to effectively accomplish the former, the resulting information asymmetry and adverse selection does have the potential to generally increase premiums, making life insurance less accessible to the average household.

   In the interest of achieving the proper balance, the Committee recommends several amendments in order to limit the financial impact on the industry while protecting the broadest swath of potential insured. These amendments are reflected in the attached mock-up.

   <u>Committee amendment #1</u>: Prohibit the use of DTC genetic tests in insurance underwriting.

   DTC genetic tests are not subject to the same standards and regulations ensuring validity as medical-grade genetic tests, and are not intended to be considered medical information. Existing law prohibits DTC genetic testing companies from providing an individual's genetic information to an insurer. Nonetheless, according to the author and sponsor, DTC genetic tests results can occasionally make their way into the medical file, resulting in access by insurers.

   To ensure that potentially unreliable information does not impact access to affordable life insurance, the Committee recommends amending the bill to prohibit the use of DTC genetic test results, even if included in the medical record, in life and disability insurance underwriting.

   <u>Committee amendment #2</u>: Permit the use of non-DTC-derived genetic information in the individual's medical record for large policies (i.e. face value in excess of $1,500,000).

   Information asymmetry and resulting adverse selection for very large policies has the potential to disproportionately impact the stability of the market. While the cost of unanticipated risk from genetic information would, for the average policy, likely be relatively low, high-risk individuals purchasing particularly large policies without insurers being able to adequately establish premiums could be quite costly, resulting in increased premiums for high- and low-risk applicants alike. According to a study by LIMRA, in 2025, the average life insurance policy in the United States had a face value of $206,000.

   As a perspective published in the scientific journal *Nature Medicine* argues:

   > A different feature worth considering, shared by the Swiss, British and now Australian models, is a monetary cap for policies above which genetic information may be used. Such caps allow insurers to hedge against risk for their most expensive policies and distribute risk on high-net-worth individuals rather than the vulnerable. If one is convinced that genetic information is not fair to use for rate setting, it may seem to be an unacceptable compromise to create exceptions above a certain monetary threshold. But pragmatically, such limits may be an effective way of aligning ethical goals with the

needs of the insurance industry. It also helps mitigate a concern of insurance companies of information asymmetry favoring underwrites who have access to their own genetic testing results.

To avert the possibility of knowingly high-risk individuals purchasing large policies under conditions of information asymmetry, the Committee recommends amending the bill to permit the use of genetic information in underwriting for policies with a face value in excess of $1,500,000. This threshold is in line with the threshold adopted in Singapore.

The amendment would also specify that insurers can only use genetic information in the individual's medical record for underwriting, as such information is presumably the subset of genetic information deemed medically pertinent.

Committee amendment #3: Remove inclusion of biomarker testing results from the bill's prohibitions.

Genetic tests are distinct from many other types of biomedical tests, e.g. blood pressure tests, in that they do not reflect the present medical state of the individual, but rather potential future conditions that may or may not emerge. The bill in print defines "biomarker" to mean "a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacological responses to a specific therapeutic intervention," and defines "biomarker testing" to mean "the analysis of an individual's tissue, blood, or other biospecimen for the presence of a biomarker." In contrast to genetic tests, these tests are indicative of the present physiological state of the body, rather than of latent genetic conditions that may not ever be expressed.

Because biomarkers are typically indicative of the actual physiology of the individual, they arguably provide critical medical information for evaluating risk. As such, the Committee recommends removing the inclusion of biomarkers and biomarker testing from the bill's prohibitions on use in underwriting.

Committee amendment #4: Clarify authorities of the Insurance Commissioner.

The bill in print provides that "the commissioner may *from time to time as conditions warrant*, promulgate reasonable rules and regulations *and amendments and additions* as necessary to administer this article."

It is unclear whether "amendments and additions" refers to amendments to the statute itself, or to the rules and regulations promulgated by the commissioner. If the former, this would represent a potentially unlawful delegation of legislative authority. If the latter, this is arguably redundant, as the authority to promulgate reasonable rules and regulations would presumably include the authority to amend or expand those rules and regulations.

To provide greater clarity, the Committee recommends striking the italicized language from the aforementioned provision.

The bill in print also specifies that "the commissioner shall have the discretion to establish what constitutes an act." Such determinations are typically the domain of the legal process and dependent on the facts of the case. As such, providing the commissioner with the sole authority to make this determination would arguably provide the commissioner with the ability to make arbitrary determinations not rooted in precedent or the facts of the case, conditions which bind the legal process.

Accordingly, the Committee recommends striking the provision granting this authority.

Committee amendment #5: Remove required exemption for genetic characteristics from the form or statement authorizing the disclosure of personal or privileged information to an insurer.

Section 791.06 of the Insurance Code details the necessary provisions of a disclosure authorization form for an insurer to receive consent to access personal information. The bill in print requires the addition of an explicit exemption for genetic information, whether in the medical record or otherwise. The existing law does not differentiate types of personal information within this provision, and as such, including this exemption may cause confusion. Pursuant to other provisions of the bill, insurers are already prohibited from seeking and using genetic information under most conditions, likely rendering this disclosure requirement redundant.

For this reason, the Committee recommends striking the requirement that the disclosure authorization form or statement include an explicit exemption of genetic information from the authorized disclosures.

Committee amendment #6, *et seq.*: Various technical and non-substantive clarifying changes reflected in the attached mock-up.

8) *Double referral.* This bill is double referred. Should it pass out of this committee, it will be heard in the Assembly Committee on Privacy & Consumer Protection.

REGISTERED SUPPORT / OPPOSITION:

Support

Als Association
Als Network
American Cancer Society Cancer Action Network INC.
American Kidney Fund
Angioma Alliance D/b/a Alliance to Cure Cavernous Malformation
Bleeding Disorders Council of California
California Chronic Care Coalition
California Life Sciences Association
Children's Specialty Care Coalition
Cure Mapt Ftd
Curegrn
Eb Research Partnership
Equality California
Force: Facing Our Risk of Cancer Empowered
Genedx
Genetic Als & Ftd: End the Legacy
Global Colon Cancer Association
Insurance Commissioner Ricardo Lara / California Department of Insurance

Natera, INC.
National Urea Cycle Disorders Foundation
Ovarian Cancer Research Alliance
Rare & Ready Coalition
Rasopathies Network
The Association for Frontotemporal Degeneration
The Everylife Foundation for Rare Diseases
The International Pemphigus and Pemphigoid Foundation
Triage Cancer
U.s. Renal Care

Opposition

American Council of Life Insurers
Association of California Life & Health Insurance Companies
National Association of Insurance and Financial Advisors - California

Analysis Prepared by: Landon Klein / INS. / (916) 319-2086