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Time to Follow Florida: Why GINA's Definition of "Genetic Information" Must Change in the Context of Life Insurance

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Time to Follow Florida: Why GINA’s Definition of “Genetic Information” Must Change in the Context of Life Insurance

Kathryn Czekalski

I.	INTRODUCTION	101
II.	BACKGROUND	104
	A. <i>Genetic Antidiscrimination Laws at the Federal Level</i>	104
	B. <i>State Regulations Regarding Use of “Genetic Information” in Life Insurance</i>	107
	C. <i>The Split: What is “Genetic Information”?</i>	109
	1. <i>The Textual Approach</i>	109
	2. <i>The Predictive Value Approach</i>	113
	D. <i>Florida’s Definition of “Genetic Information”</i>	116
III.	ANALYSIS	117
	A. <i>Comparative Analysis of Both Definitions in the Life Insurance Context Under GINA</i>	118
	B. <i>Why Genetic Antidiscrimination Advocates Should Urge Legislatures to Adopt Florida’s Definition in the Life Insurance Context</i>	120
IV.	CONCLUSION.....	123

I. INTRODUCTION

Many Americans apply for a life insurance policy to protect their spouses and families in the event of an untimely death.¹ What if insurance companies required genetic tests as part of the application process? What if those results were used to exclude applicants or calculate premiums? Can an individual who has taken a

1. For example, in 2021, over fifty percent of Americans owned a life insurance policy. *Life Insurance Ownership in the U.S. 2021*, STATISTA, <https://www.statista.com/statistics/455614/life-insurance-ownership-usa/> (last visited July 28, 2021).

commercial genetic test, such as the popular 23andMe,² be forced to disclose the results to obtain an insurance policy? Surprisingly, genetic discrimination regarding life insurance decisions is currently legal in forty-nine of the fifty states.³ This Article argues that additional federal legislation to prohibit genetic discrimination, modeled after existing Florida law, is necessary to protect against genetic discrimination involving life insurance.

In the United States, the Genetic Information Nondiscrimination Act of 2008 (“GINA”) is the main source for antidiscrimination law surrounding an individual’s “genetic information.”⁴ GINA accomplishes this goal with two main components: Title I and Title II.⁵ Title I prohibits health insurance companies from using genetic information to discriminate in issuing health insurance.⁶ But that prohibition does *not* extend to genetic discrimination involving life, disability, or long-term care insurance.⁷ Title II prohibits employers from using genetic information to discriminate in the employment context.⁸

Between Title I and Title II, GINA has made a bigger impact in the employment context, with a handful of courts finding that employers unlawfully requested or used genetic information to discriminate in employment decisions.⁹ However, outside of employment and health insurance, genetic discrimination is not prohibited

2. 23andMe offers personal genetics services that require submission of a saliva sample that the consumer sends to the lab for analysis. 23ANDME, <https://www.23andme.com/how-itworks/> (last visited Feb. 25, 2021).

3. Mark A. Rothstein & Kyle B. Brothers, *Banning Genetic Discrimination in Life Insurance – Time to Follow Florida’s Lead*, 383 NEW ENG. J. MED. 2099, 2099 (2020).

4. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified as amended at scattered sections of United States Code Titles 26, 29, and 42) [hereinafter GINA].

5. *Id.* §§ 101–102.

6. *Id.* Title I applies to employer-sponsored group health plans and health insurers providing group health coverage. *Id.* § 101. It also applies to individual health coverage. *Id.* § 102. GINA also covers state and local federal government plans, including Medigap. See Sonia M. Souter, *GINA at 10 Years: The Battle Over ‘Genetic Information’ Continues in Court*, 5 J.L. & BIOSCIENCES 495, 500 (2018).

7. Anya E.R. Prince, *Insurance Risk Classification in an Era of Genomics: Is a Rational Discrimination Policy Rational?*, 96 NEB. L. REV. 626, 626 (2018) (“Other insurers, such as life, long-term care, and disability insurers, are exempt from the [GINA].”) [hereinafter Insurance Risk Classification].

8. GINA § 202(a); see discussion *infra* Section II.

9. See, e.g., EEOC v. Grisham Farm Prods., 191 F. Supp. 3d 994, 998 (W.D. Mo. 2016) (holding that an employment application requiring disclosure of conditions that were not yet manifested constituted unlawful solicitation of information under GINA); Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC, No. 1:13-CV-2425-AT, 2015 U.S. Dist. LEXIS 178275, at *8 (N.D. Ga. Sept. 28, 2015) (ordering plaintiffs’ employer to pay \$600,000 in damages after unlawfully collecting genetic samples under GINA to resolve a workplace dispute). See also Souter, *supra* note 6, at 505.

under federal law.¹⁰ To fill this gap, some states have enacted their own legislation to protect against genetic discrimination in many other industries, including non-medical insurance, housing, education, mortgage lending, and even elections.¹¹

In addition to problems with GINA's coverage limits, courts have not uniformly interpreted the term "genetic information."¹² Courts have essentially settled on two possible interpretations.¹³ One definition interprets the term to mean literally any type of genetic information, while the other definition only considers genetic information that shows the propensity of disease.¹⁴ At the state level, Florida has recently passed a law which applies GINA's antidiscrimination principles to life insurance decisions, but the statute has an even more narrow definition of "genetic information" than GINA.¹⁵ While many genetic antidiscrimination activists are trying to amend GINA to cover more industries like life insurance, a balance must be struck between the interests of the companies writing the policies and those whom they insure.¹⁶

First, this Article will explore a detailed background of GINA's history, as well as Florida's new law passed in Summer 2020.¹⁷ The Article will analyze how federal genetic antidiscrimination caselaw yields different definitions of "genetic information."¹⁸ The Article will highlight the problems with incorporating those definitions (and Florida's new, narrow definition) into the life insurance context.¹⁹ This Article will conclude with reform proposals to create a sensible approach to prohibiting genetic discrimination in life insurance. Ultimately, this Article proposes that life insurance companies should be prohibited from requiring specific genetic testing (or inquiring about genetic testing) in an application or as part of

10. See Souter, *supra* note 6, at 498–99.

11. See, e.g., FLA. STAT. § 627.4301 (2020). See also S.B. 559, 2011 Leg., Reg. Sess. (Cal. 2011) (prohibiting genetic discrimination on the basis of genetic information by adding it to the list of characteristics in the Unruh Civil Rights Act).

12. "In the last 10 years . . . the courts have been divided over how to interpret GINA's definition of 'genetic information' . . ." Souter, *supra* note 6, at 499–500. See also discussion *infra* Section II(c).

13. See discussion *infra* Section II(c).

14. See Souter, *supra* note 6, at 499–500. See also discussion *infra* Section II(c).

15. FLA. STAT. § 627.4301 ("Genetic information' means information derived from genetic testing to determine the presence or absence of variations or mutations . . . in an individual's genetic material or genes that are scientifically or medically believed to cause a disease . . . which is asymptomatic at the time of testing.") (emphasis added).

16. See, e.g., Insurance Risk Classification, *supra* note 7, at 627; Rothstein & Brothers, *supra* note 3, at 2100.

17. See generally FLA. STAT. § 627.4301.

18. See Souter, *supra* note 6, at 499–500.

19. See discussion *infra* Section II(c)–(d).

the disclosure process, while allowing insurers to continue asking applicants questions about family history.

II. BACKGROUND

A. *Genetic Antidiscrimination Laws at the Federal Level*

Before GINA existed, a well-known federal law prohibited the use of genetic information in healthcare decisions, similar to GINA's Title I.²⁰ Federal protection of genetic information began with the Health Information Portability and Accountability Act ("HIPAA").²¹ Enacted in 1996, HIPAA is best known for its medical privacy provisions, not necessarily its impact in genetic antidiscrimination.²² However, the law aimed to eliminate "job lock," a term given to people who were afraid to leave their employer because the switch in insurance would make them lose coverage or incur long waiting periods due to a preexisting condition.²³ In codifying this aim, HIPAA included regulations regarding what insurers could and could not use to exclude or limit coverage.²⁴

HIPAA added Section 702 to the Employee Retirement Income Security Act of 1974, which included a list of "health status-related factors" that group health insurers *may not use* to discriminate against individual participants and beneficiaries.²⁵ Among the factors is "genetic information,"²⁶ the definition of which specifies that this term constitutes genetic conditions that have not yet manifested.²⁷ In other words, if a patient had genetic information in his or her file that did not manifest itself into a diagnosable condition, then that genetic information could not be used to limit or exclude coverage prior to enrollment.²⁸

20. See Souter, *supra* note 6, at 498.

21. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified as amended in scattered sections of United States Code, Titles 18, 26, 29, and 42) [hereinafter HIPAA].

22. See Julie Rovner, *Did the ACA Create Preexisting Condition Protections for People in Employer Plans?*, KHN (May 21, 2019), <https://khn.org/news/did-the-aca-create-preexisting-condition-protections-for-people-in-employer-plans/>.

23. See generally Rebecca Lewin, *Job Lock: Will HIPAA Solve the Job Mobility Problem?*, 2 U. PA. J. LAB. & EMP. L. 507, 507-08 (2000).

24. See, e.g., HIPAA § 702(a).

25. *Id.* § 702(a)(1).

26. *Id.* § 702(a)(1)(F).

27. *Id.* § 701(b)(1)(B).

28. This is a key distinction. For example, a woman may test positive for the gene that has mutations associated with a high risk of breast cancer. However, she does not have breast cancer simply because she has a gene that tends to indicate a higher rate of eventual diagnosis. Therefore, under the HIPAA protections only, she could not be excluded from or reduced to limited coverage on her employer-sponsored plan based on this gene mutation

By the mid-2000s, following scientific innovation in the study of genomics, most states enacted laws prohibiting genetic discrimination in health insurance.²⁹ HIPAA, however, preempted state genetic discrimination laws regarding employer-sponsored group health insurance plans.³⁰ While HIPAA prohibited genetic discrimination in these plans, it did not prevent insurers from *asking* for genetic information or *demanding* genetic tests.³¹ Additionally, HIPAA did not apply to individual health insurance plans or non-employer plans.³²

Thus, with relatively little protection at the federal level outside of this narrow HIPAA provision,³³ Congress heeded the demand from the genetic testing companies for more comprehensive federal legislation and enacted GINA in 2008.³⁴ GINA's model encompassed a complete ban on using genetic information to discriminate in health insurance and employment.³⁵ Results of an individual's genetic tests can yield information about gene mutations, hereditary traits, and even asymptomatic disease.³⁶ This information is extremely personal, warranting protection at the federal level.³⁷

GINA's Title I amended federal laws to extend antidiscrimination requirements to health insurers providing group health insurance

without an actual breast cancer diagnosis. See generally *BRCA: The Breast Cancer Gene*, NAT'L BREAST CANCER FOUND., <https://www.nationalbreastcancer.org/what-is-brca> (last visited Feb. 25, 2021) (explaining the BRCA mutation and detection methods).

29. Mark A. Rothstein, *Is GINA Worth the Wait?*, 36 J.L. MED. & ETHICS 174, 174–75 (2008).

30. *Id.* Employer sponsored plans are by far the most popular in the United States, with almost sixty percent of the nonelderly United States population participating in an employer-sponsored plan in 2008. Matthew Rae et al., *Long-Term Trends in Employer-Based Coverage*, HEALTH SYS. TRACKER (Apr. 3, 2020), <https://www.healthsystemtracker.org/brief/long-term-trends-in-employer-based-coverage/>. So, it is unsurprising that HIPAA chose only to cover this source of health insurance. However, the number of people relying on employer-sponsored plans was and is declining. *Id.*

31. Souter, *supra* note 6, at 498 n.21.

32. *Id.*

33. In 2000, an executive order prohibited genetic discrimination in federal employment. Rothstein, *supra* note 29, at 175. The Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 [hereinafter ADA], prohibited discrimination based on disabilities, but subsequent Supreme Court decisions made it very clear that the ADA was to be construed narrowly and would not apply to asymptomatic genetic discrimination. Rothstein, *supra* note 29, at 175.

34. The lobbyists that were in favor of GINA were genetics researchers, biotech companies, pharmaceutical companies, and the genetic testing companies because all of their efforts and developments would be fruitless if people were afraid to undergo genetic testing due to potential discrimination. Rothstein, *supra* note 29, at 176.

35. See Anya E. R. Prince, *Political Economy, Stakeholder Voices, and Saliency: Lessons from International Policies Regulating Insurer Use of Genetic Information*, 5 J.L. & BIOSCIENCES 461, 462–63 (2018) [hereinafter International Genetic Information Policies].

36. See *Genetic Testing FAQ*, NAT'L HUMAN GENOME RSCH. INST., <https://www.genome.gov/FAQ/Genetic-Testing> (last updated Feb. 13, 2019).

37. See *id.*

or individual health insurance.³⁸ It imposes a ban on genetic discrimination by proscribing what constitutes discriminatory uses of “genetic information.”³⁹ The Act defines “genetic information” as “information about (i) such an individual’s genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual.”⁴⁰ GINA prohibits requesting, requiring, or even purchasing someone’s genetic information for underwriting.⁴¹ Additionally, health insurers may not require insureds or their family members to undergo genetic testing.⁴²

Likewise, Title II also describes the discriminatory uses of genetic information as they apply to employment decisions.⁴³ Employment decisions include “hiring; discharging; determining compensation, terms, conditions, and privileges of employment; or limiting, segregating, or classifying an employee in ways that could deprive the employee of employment opportunities or ‘adversely affect the status of the employee’ based on genetic information.”⁴⁴ GINA also prohibits employers from acquiring genetic information, meaning that, generally, employers cannot “request, require, or purchase” an employee’s genetic information.⁴⁵ Notably, GINA does not apply to private employers with fewer than fifteen employees.⁴⁶

GINA yielded robust standards in some areas, like employment law.⁴⁷ It also created more questions about what constitutes “genetic information.”⁴⁸ GINA’s protections also do not extend beyond health insurers, and thus exclude long-term care, disability, and life insurers.⁴⁹ Despite these gaps, many hailed GINA as a modern civil rights act.⁵⁰ Senator Ted Kennedy called GINA the “first civil rights

38. Souter, *supra* note 6, at 500–01. GINA included the same stipulation for employer-sponsored health plans, though already covered by HIPAA. *Id.* at 500.

39. *Id.*

40. GINA § 201(4)(A)(i)–(iii).

41. Souter, *supra* note 6, at 501.

42. *Id.*

43. *Id.*

44. *Id.* at 501–02 (quoting GINA § 202(b)).

45. GINA § 202(b). Some exceptions are noted, such as for wellness programs that ask for voluntary information that employers will not see unless it is anonymous. GINA § 202(b)(1)–(5).

46. Questions and Answers for Small Businesses: EEOC Final Rule on Title II of the Genetic Information Nondiscrimination Act of 2008, EQUAL OPPORTUNITY EMP. COMM’N (Nov. 9, 2010) <https://www.eeoc.gov/laws/guidance/questions-and-answers-small-businesses-eeoc-final-rule-title-ii-genetic-information>.

47. See *EEOC v. Grisham Farm Prods.*, 191 F. Supp. 3d 994, 997–98 (W.D. Mo. 2016). This case is discussed in-depth in Section II(c)(i), *infra*.

48. See Souter, *supra* note 6, at 499–500.

49. Insurance Risk Classification, *supra* note 7, at 626.

50. Souter, *supra* note 6, at 496.

bill of the new century of the life sciences.”⁵¹ Indeed, this legislation was a major milestone in protecting Americans, but several states have since passed more limits on genetic discrimination.⁵²

B. State Regulations Regarding Use of “Genetic Information” in Life Insurance

GINA purposely did not encompass other forms of insurance, such as life insurance.⁵³ Life insurance is a type of insurance that pays a death benefit to an insured’s beneficiaries.⁵⁴ An insured guarantees coverage amounts by paying a premium, which is determined by a number of factors such as age, health status, personal and family medical history, lifestyle, environmental exposures, and other factors.⁵⁵ Genetic information has been available for life insurance companies to utilize when issuing policies, but Florida is making significant changes in this regard.⁵⁶

Contemporaneously, several experts have conducted studies to argue that federal genetic antidiscrimination laws should extend to other areas, such as life insurance.⁵⁷ In fact, studies have shown that the fear of genetic discrimination has inhibited individuals from undergoing recommended testing.⁵⁸ Another study showed that twenty-five percent of people who elected not to participate in genetic sequencing research cited fear of discrimination by life insurance companies.⁵⁹

Florida recently emerged as a genetic antidiscrimination leader. In Summer 2020, Governor Ron DeSantis signed House Bill 1189, which amended a Florida statute that regulates genetic information for health insurance purposes.⁶⁰ The amended statute changed existing law⁶¹ to extend genetic discrimination protections to life

51. *Id.*

52. See Rothstein & Brothers, *supra* note 3, at 2100.

53. Souter, *supra* note 6, at 499 n.26 (citing Sarah Zhang, *The Loopholes in the Law Prohibiting Genetic Discrimination*, ATLANTIC (Mar. 13, 2017), <https://www.theatlantic.com/health/archive/2017/03/genetic-discrimination-law-gina/519216/>).

54. *Industry Overview: Life Insurance*, VALUE LINE, https://www.valueline.com/Stocks/Industries/Industry_Overview__Life_Insurance.aspx (last visited Feb. 24, 2021).

55. *Id.* See also Rothstein & Brothers, *supra* note 3, at 2100.

56. See Souter, *supra* note 6, at 498; Rothstein & Brothers, *supra* note 3, at 2100.

57. See International Genetic Information Policies, *supra* note 35, at 466.

58. *Id.* at 467 n.32.

59. Rothstein & Brothers, *supra* note 3, at 2100.

60. John Haughey, *Florida Becomes First State to Enact a DNA Privacy Law, Blocking Insurers from Genetic Data*, CTR. SQUARE (July 1, 2020), https://www.thecentersquare.com/florida/florida-becomes-first-state-to-enact-dna-privacy-law-blocking-insurers-from-genetic-data/article_19acb7fc-bbe2-11ea-a88d-bf2dbe8939af.html.

61. FLA. STAT. § 627.4301 (2020).

insurance.⁶² Specifically, the law “prohibit[s] life insurers . . . from canceling, limiting, or denying coverage, or establishing differentials in premium rates based on genetic information under certain circumstances.”⁶³ These “certain circumstances” include underwriting and issuing policies,⁶⁴ and explicitly exclude official diagnoses made based on the results of a genetic test.⁶⁵ The law also provides that life insurers “may not require or solicit genetic information, use genetic test results, or consider a person’s decisions or actions relating to genetic testing in any manner for any insurance purpose.”⁶⁶

Substantively, Florida’s law is more narrowly defined than GINA in its statutory definition of “genetic information.”⁶⁷ House Bill 1189 defines “genetic information” as:

[I]nformation derived from genetic testing to determine . . . [the existence of] 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.⁶⁸

Notably, the law excludes questions regarding family history from this definition.⁶⁹ House Bill 1189 is the first law to outright *prohibit* the use of genetic information in life insurance and long-term care in the United States.⁷⁰ Other states have imposed limited protections on genetic information.⁷¹ For example, Colorado has banned the use of genetic information in long-term care insurance but not in life insurance.⁷² Additionally, California prohibits the use of genetic information in a coverage decision where a denial would discriminate against unaffected carriers of genes for recessive disorders; and Vermont prohibits life insurers conditioning a policy on genetic testing, even though insurers may utilize clinical

62. *Id.*

63. H.B. 1159, 2020 Leg., Reg. Sess. (Fla. 2020).

64. FLA. STAT. § 627.4301(2)(a).

65. *Id.* § 627.4301(2)(d).

66. *Id.* § 627.4301(2)(b).

67. Compare *id.* § 627.4301(1)(a) with Souter, *supra* note 6, at 502 (discussing the definition of “genetic information” from GINA).

68. FLA. STAT. § 627.4301(1)(a).

69. *Id.* § 627.4301(1)(a) (“Such testing does not include . . . questions regarding family history.”).

70. Rothstein & Brothers, *supra* note 3, at 2099.

71. International Genetic Information Policies, *supra* note 35, at 469.

72. *Id.*

genetic test results in underwriting.⁷³ However, no state had ever banned the use of genetic discrimination in life insurance prior to Florida.⁷⁴

The Florida law will impact a small number of people with certain genetic conditions, particularly those with fatal, adult-onset diseases without a documented family history, who would have undoubtedly experienced discrimination with genetic test results indicating as much before applying for a policy.⁷⁵ In the greater context, many people with a significant likelihood of developing certain forms of cancer or heart disease will not have reluctance to undergo genetic testing to improve their prognoses because life insurance companies can no longer use that information to withhold coverage.⁷⁶

C. *The Split: What is “Genetic Information”?*

GINA is the rare type of preemptive antidiscrimination legislation enacted before discrimination was widespread or practical, and it came to fruition mostly because of what was unknown and feared.⁷⁷ Despite little evidence to support its enactment, GINA has spurred several court decisions, mostly in the employment discrimination context.⁷⁸ Courts have adopted two different interpretations of the meaning of “genetic information.”⁷⁹ This has resulted in an inconsistent application of the federal law, with future courts potentially facing a choice to adopt one of these definitions.⁸⁰

1. *The Textual Approach*

The most infamous case concerning genetic discrimination in the employment context is *Lowe v. Atlas Logistics Group Retail Services*

73. Rothstein & Brothers, *supra* note 3, at 2100.

74. *Id.* at 2099.

75. *Id.* at 2100.

76. *Id.* For example, Myriad Oncology offers genetic testing to “aid in identifying ovarian cancer patients with positive homologous recombination deficiency (HRD) status, who are eligible” for treatment with “targeted therapy” with certain medications associated with a better prognosis. *Germline Testing*, MYRIAD ONCOLOGY, <https://myriad-oncology.com/my-choice-cdx/germline-testing/> (last visited Feb. 25, 2021).

77. See generally Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 441, 443 (2010) (“While some examples do exist, both GINA’s advocates and adversaries agreed that scant evidence indicated a significant history of genetic-information discrimination.”). See also Souter, *supra* note 6, at 498.

78. Souter, *supra* note 6, at 505. A handful of these cases will be discussed in Section II(c)(i)–(ii), *infra*.

79. *Id.* at 506.

80. See *id.*

(*Atlanta*), LLC, otherwise known as the “Devious Defecator Case.”⁸¹ Atlas Logistics Group Retail Services (Atlanta), LLC (“Atlas”), owned a warehouse where it stored products to be sold at grocery stores.⁸² In the storage space, an unknown employee began “habitually defecating,” requiring products to be destroyed.⁸³ After an internal investigation, a supervisor suspected two employees, Lowe and Reynolds.⁸⁴ Atlas required the men to submit their DNA to a third-party lab for comparison with the fecal matter.⁸⁵ Neither suspect was a match.⁸⁶

Lowe and Reynolds subsequently sued Atlas in the United States District Court for the Northern District of Georgia, alleging that Atlas violated GINA.⁸⁷ At issue were the parties’ different definitions of “genetic information.”⁸⁸ Lowe and Reynolds argued that when Atlas required them to undergo DNA collection by swabbing their mouths, the company took prohibited “genetic information” consistent with GINA’s statutory definition.⁸⁹ Conversely, Atlas argued that the DNA obtained from the employees was not “genetic information” as defined by GINA.⁹⁰ In Atlas’s view, “genetic information” was only “information related to an individual’s propensity for disease.”⁹¹ Both parties moved for summary judgement.⁹²

The court analyzed GINA’s definition of “genetic information,” and determined that “information about . . . [an] individual’s genetic tests” was “unambiguous.”⁹³ Additionally, the court examined how GINA defined “genetic test,” which is “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.”⁹⁴ The court concluded that by GINA’s own definitions, the DNA samples clearly fell within the meaning of “genetic information” because the lab analyzed

81. 102 F. Supp. 3d 1360 (N.D. Ga. 2015); Souter, *supra* note 6, at 515 (quoting Gina Kolata, ‘Devious Defecator’ Case Tests Genetics Law, N.Y. TIMES (May 29, 2015), <https://www.nytimes.com/2015/06/02/health/devious-defecator-case-tests-genetics-law.html>).

82. *Lowe*, 102 F. Supp. 3d at 1361.

83. *Id.*

84. *Id.* at 1362–63.

85. *Id.* at 1363.

86. *Id.*

87. *Id.* Lowe and Reynolds first filed discrimination charges with the EEOC, but the EEOC dismissed the charges and made no finding that Atlas violated GINA. *Id.* at 1363–64. They were entitled to file suit within ninety days of the EEOC’s findings, which they did. *Id.* at 1364.

88. *Id.*

89. *Id.*

90. *Id.*

91. *Id.*

92. *Id.*

93. *Id.* at 1365.

94. *Id.*

Lowe's and Reynolds's DNA in a way that detected genotypes and mutations.⁹⁵

The court rejected Atlas's interpretation of "genetic information" under GINA.⁹⁶ In its own interpretation of the statute, the court examined GINA's legislative intent, and found that GINA's purpose was "to 'establish a national and uniform basic standard' of unacceptable use of genetic information in health insurance and employment[.]"⁹⁷ The court explained that the legislators understood that not all genetic tests indicate propensity for disease, and they refused to narrow the definition despite this knowledge.⁹⁸ Ultimately, the court found the narrower definition urged by Atlas unpersuasive and declined to adopt it.⁹⁹ Thus, relying only on the broad, "unambiguous" statutory definition in its application of the law, the court held that Atlas had violated GINA and was liable to Lowe and Reynolds.¹⁰⁰ After the trial on damages, the court ordered Atlas to pay Lowe and Reynolds \$300,000 each.¹⁰¹

Similarly, in *EEOC v. Grisham Farm Products*, the court followed the broad statutory definition in its application of GINA's definition of "genetic information," just as the court did in *Lowe*.¹⁰² In this case, Phillip Sullivan ("Sullivan") applied to Grisham Farm Products' ("Grisham Farm") warehouse job-listing by downloading the application from the company website.¹⁰³ The application required him to answer forty-three questions about his health history.¹⁰⁴ Included in the questions was whether Sullivan had "consulted a healthcare provider within the past twenty-four months regardless of whether he had been diagnosed with a particular condition, or [sought] advice, diagnosis or treatment from a healthcare provider."¹⁰⁵

Sullivan did not complete or submit the application and notified the Equal Employment Opportunity Commission ("EEOC"), where he then filed a charge of discrimination.¹⁰⁶ Among Sullivan's claims was that Grisham Farm violated GINA, and he moved for

95. *Id.*

96. *Id.* at 1366.

97. *Id.* at 1367 (quoting 42 U.S.C. § 2000ff).

98. *Id.* at 1368.

99. *Id.* at 1369.

100. *Id.* at 1370.

101. *Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC*, No. 1:13-CV-2425-AT, 2015 U.S. Dist. LEXIS 178275, at *8 (N.D. Ga. Sept. 28, 2015).

102. 191 F. Supp 3d 994, 997 (W.D. Mo. 2016).

103. *Id.* at 995.

104. *Id.*

105. *Id.* (internal quotations omitted).

106. *Id.*

judgement on the pleadings.¹⁰⁷ The court referred to GINA's statutory language in stating that the prohibition against requesting genetic information extended to employment applications that request "information about an individual's current health status in a way that is likely to result in a covered entity obtaining genetic information."¹⁰⁸

Based on its reading of the statutory language, the court determined that the questions asking whether the applicant had consulted a health care provider could require disclosure of preventative care for asymptomatic disease.¹⁰⁹ The court used an example of an applicant who had preventatively consulted with their physician to get genetic testing due to a family history of breast cancer.¹¹⁰ A required disclosure of such information would be a direct violation of GINA.¹¹¹ As a result, the court granted summary judgement in favor of Sullivan and ordered Grisham Farm to pay \$5,000 in damages for the violation of GINA.¹¹²

The textual approach tracks the statutory text, and courts *only* look to the statutory definitions of GINA to determine whether information constitutes "genetic information."¹¹³ If the information falls into any of the enumerated categories in GINA, the statute applies regardless of whether the information would be used to predict the "propensity of disease."¹¹⁴ This approach is more akin to a strict-liability theory in determining what constitutes "genetic information."¹¹⁵ Other cases have also followed this framework under various sets of facts.¹¹⁶ However, this analysis has coexisted with a

107. *See id.* at 995–97 ("A motion for judgment on the pleadings will be granted 'where the moving party has clearly established that no material issue of fact remains and the moving party is entitled to judgment as a matter of law.'") (quoting *Waldron v. Boeing Co.*, 388 F.3d 591, 593 (8th Cir. 2004)).

108. *Id.* at 997.

109. *See id.*

110. *Id.* at 998.

111. *Id.*

112. *Id.* The damages were calculated based on Sullivan's "failure to gain employment, inconvenience, embarrassment, and loss of enjoyment of life." *Id.* at 995.

113. The term "textual approach" is apt because courts following *Lowe* have not examined GINA's legislative intent and relied only on the broad statutory definition that *Lowe* ultimately endorsed. *See id.* at 997. Thus, this term describes the way courts determine whether certain data constitutes genetic information, *not* the process the *Lowe* court utilized in deciding to apply only the broad statutory definition. *Id.*

114. *See generally* *Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC*, 102 F. Supp. 3d 1360, 1365–66 (N.D. Ga. 2015).

115. *See* Souter, *supra* note 6, at 511 (discussing the implications of considering family medical history as "genetic information" as a matter of law).

116. *See, e.g.,* *Montgomery v. Union Pac. R.R. Co.*, No. CV-17-00201-TUC-RM, 2018 U.S. Dist. LEXIS 198593, at *9 (D. Ariz. Nov. 21, 2018) (concluding that an employer unlawfully requested genetic information in a medical history form that did not include "instructions to redact family history"); *Jackson v. Regal Beloit Am., Inc.*, No. 16-134-DLB-CJS, 2018 U.S.

stricter definition of “genetic information,” termed here the predictive value definition.¹¹⁷

2. *The Predictive Value Approach*

The backstory surrounding the seminal case for the predictive value definition of “genetic information” is substantially less humorous than its counterpart in *Lowe*. In *Poore v. Peterbilt of Bristol, L.L.C.*, plaintiff Mark Poore (“Poore”) was employed by Peterbilt of Bristol, L.L.C. (“Peterbilt”) from 2005 to 2010.¹¹⁸ While employed, he received health insurance coverage for himself and his family.¹¹⁹ Following an acquisition by new owners, Poore’s office manager required him to fill out a health insurance form concerning his family’s medical conditions and medications.¹²⁰ Poore’s wife was diagnosed with multiple sclerosis, which he disclosed.¹²¹ Shortly thereafter, the office manager asked Poore follow-up questions regarding Poore’s wife’s diagnosis, including when she had been diagnosed and her prognosis.¹²² Three days later, Peterbilt terminated Poore without “sufficient explanation.”¹²³

Poore filed suit against Peterbilt for discrimination, and among his claims was an assertion that Peterbilt had violated GINA by collecting genetic information.¹²⁴ Peterbilt moved to dismiss the alleged GINA violation for failure to state a claim.¹²⁵ The court looked to GINA’s statutory definition of “genetic information,” as well as the language that stipulates that it is illegal for an employer to “discharge[] any employee, or otherwise discriminate against any employee . . . because of *genetic information with respect to the employee.*”¹²⁶ The court also referred to the EEOC’s clarification that “‘manifestation of a disease or disorder in family members’ refers to an employee’s ‘family medical history.’”¹²⁷

Dist. LEXIS 103682, at *15-16 (E.D. Ky. Jun. 21, 2018) (determining that a physician performing an employment-related medical exam unlawfully requested genetic information by requesting medical records that “contained protected genetic information in the form of her family history”) (internal quotations omitted); *Punt v. Kelly Servs.*, No. 14-cv-02560-CMA-MJW, 2016 WL 67654, at *13 (D. Colo. June 6, 2016) (holding that familial cancer constitutes genetic information because it “is the type of genetic information implicated by GINA”).

117. Souter, *supra* note 6, at 506.

118. 852 F. Supp. 2d 727, 729 (W.D. Va. 2012).

119. *Id.*

120. *Id.*

121. *Id.*

122. *Id.*

123. *Id.*

124. *Id.*

125. *Id.*

126. *Id.* at 730–31 (emphasis in original) (quoting 42 U.S.C. § 2000ff-1(a)).

127. *Id.* at 730.

In addition to construing the statute, the court examined the legislative intent of GINA.¹²⁸ Unlike the *Lowe* case, the *Poore* court utilized this information to *narrow* the definition of “genetic information.”¹²⁹ Specifically, the court cited congressional reports in formulating its rule:

Congress included family medical history in the definition of “genetic information” because it understood that employers could potentially use family medical history “as a surrogate for genetic traits.” . . . However, the fact that an individual family member merely has been diagnosed with a disease or disorder is not considered “genetic information” if “such information is taken into account only with respect to the individual in which such disease or disorder occurs and not as genetic information with respect to any other individual.”¹³⁰

Ultimately, the court analyzed Poore’s wife’s diagnosis to have “no predictive value with respect to Poore’s genetic propensity to acquire the disease[.]” and so Peterbilt did not violate GINA.¹³¹ Therefore, the court dismissed Poore’s GINA claims.¹³²

In a scholarly analysis of the difference between the court’s reasoning in *Poore* and the broader definition of “genetic information,” Sonia Souter notes that there is “logic to the *Poore* opinion.”¹³³ In fact, it does make sense that one spouse’s medical history is not indicative of the other’s propensity for disease. However, Souter points out that the *Poore* court did not consider the meaning of “family members” as it relates to GINA’s definition of “genetic information.”¹³⁴ Souter argues that Poore’s wife was a “family member” and her diagnosis was a “manifested condition,” covered under GINA’s definition of “genetic information.”¹³⁵

The *Poore* decision, according to Souter, laid the groundwork for the “two-tiered interpretative approach” that other courts followed.¹³⁶ Souter defines the approach as “a determination of (1) whether a manifested disease or disorder exists in a family member and (2) whether information about a family member’s disease or

128. *Id.*

129. *Id.* at 731.

130. *Id.* at 730–31 (citations omitted) (quoting H.R. Rep. No. 110-28, pt. 2, at 27 (2007)).

131. *Id.* at 731.

132. *Id.*

133. Souter, *supra* note 6, at 507.

134. *Id.*

135. *Id.* at 508.

136. *Id.*

disorder is ‘taken into’ account in determining whether the employee has a propensity for disease.”¹³⁷

Evidence of this problematic test is more readily apparent in *Maxwell v. Verde Valley Ambulance*.¹³⁸ In this case, Matthew Maxwell (“Maxwell”) worked for Verde Valley Ambulance Company (“VVAC”) from 2005 to 2011.¹³⁹ Prior to working for VVAC, Maxwell suffered a serious leg injury in a motorcycle accident, which became an issue when VVAC moved to a new building with stairs.¹⁴⁰ VVAC required Maxwell to undergo a medical evaluation to determine if he was disabled.¹⁴¹ VVAC received a copy of the evaluation, which included Maxwell’s disclosure of a family medical history, on which Maxwell had indicated that his grandfather had cancer.¹⁴² The medical evaluation deemed Maxwell was not disabled due to his leg injury, and VVAC terminated Maxwell two days later.¹⁴³

Maxwell filed discrimination charges with the EEOC and alleged that VVAC violated GINA by “requiring him to disclose ‘genetic information’ in his family medical history[.]”¹⁴⁴ On cross-motions for summary judgment, the court had to decide whether Maxwell’s disclosure of his grandfather’s cancer constituted “genetic information” under GINA.¹⁴⁵

The court first analyzed the statutory language, noting that the prohibition on employers requesting genetic information extended to the employee and family members of the employee.¹⁴⁶ However, the court relied on *Poore*, appealing to GINA’s intention to “prohibit employers from making a ‘predictive assessment concerning an individual’s propensity to get an inheritable genetic disease or disorder based on the occurrence of an inheritable disease or disorder in [a] family member.’”¹⁴⁷ Using the test from *Poore*, the court rejected the strict liability theory present in the textual approach and denied both motions for summary judgment.¹⁴⁸ In its analysis, the court reasoned that nothing in the record showed that VVAC had

137. *Id.*

138. No. CV-13-08044-PCT-BSB, 2014 U.S. Dist. LEXIS 127370 (D. Ariz. Sept. 11, 2014).

139. *Id.* at *3–6.

140. *Id.*

141. *Id.* at *6.

142. *Id.* at *38–39.

143. *Id.* at *6–7.

144. *Id.* at *40.

145. *Id.* at *40–41.

146. *Id.* at *41–42.

147. *Id.* at *47 (alteration in original) (quoting *Poore v. Peterbilt of Bristol, L.L.C.*, 852 F. Supp. 2d 727, 730 (W.D. Va. 2012)).

148. *Id.* at *48–49.

“taken into account” Maxwell’s disclosure of his grandfather’s cancer in the decision to fire him.¹⁴⁹

This case is at odds with the textual approach to determine the scope of “genetic information” because here, there is “genetic information” that is potentially predictive of an employee’s propensity for disease.¹⁵⁰ Cancer can have a genetic component.¹⁵¹ This is different from *Poore*, where the plaintiff’s wife’s diagnosis could not predict his future health.¹⁵²

D. Florida’s Definition of “Genetic Information”

Although there is not yet any case law from Florida’s new life insurance regulation, the Florida legislature’s choice in defining genetic information strongly indicates that it has chosen to adopt the predictive value definition of “genetic information.”¹⁵³ The main difference between Florida’s and GINA’s definitions of “genetic information” is that Florida defines the term as the “results of predictive genetic tests” for an individual only.¹⁵⁴ GINA includes a family member’s genetic tests and manifested conditions in its definition, which Florida specifically excludes.¹⁵⁵ Florida’s definition also only covers genetic information in relation to genetic test results.¹⁵⁶ Even the predictive value cases discussed in this Article did not make such a distinction, as the *Maxwell* case could have ruled the other way if the employer had “taken [it] into account.”¹⁵⁷

Even though Florida appears to have selected the predictive value definition to guide its life insurance companies, other states have adopted the textual approach for their genetic antidiscrimination laws.¹⁵⁸ For example, California has adopted nearly an

149. *Id.* at *48.

150. Souter, *supra* note 6, at 511.

151. *Id.*

152. *See id.* Other courts have also signaled they would endorse *Poore*. *See, e.g.*, Gibson v. Wayfair, Inc., No. 4:17-2059, 2018 U.S. Dist. LEXIS 107425, at *11 (S.D. Tex. June 27, 2018) (citing *Poore*’s definition of genetic information in dictum); Green v. Whataburger Rests. LLC, No. 5:17-CV-243-DAE, 2018 U.S. Dist. LEXIS 240112, at *2 (W.D. Tex. Feb. 22, 2018) (suggesting in dictum that *Poore*’s tiered framework applied and that a plaintiff must show that genetic information has predictive value to prevail on a GINA claim).

153. Rothstein & Brothers, *supra* note 3, at 2099.

154. *Id.*

155. FLA. STAT. § 627.4301(1)(a); *cf.* Souter, *supra* note 6, at 502 (“genetic information” is “information about (i) such an individual’s genetic tests, (ii) the genetic tests of family members of such individual, and (iii) the manifestation of a disease or disorder in family members of such individual”).

156. Rothstein & Brothers, *supra* note 3, at 2099.

157. *See Maxwell v. Verde Valley Ambulance*, No. CV-13-08044-PCT-BSB, 2014 U.S. Dist. LEXIS 127370, at *47 (D. Ariz. Sept. 11, 2014).

158. *See California Genetic Information Non-discrimination Act (CalGINA)*, S.B. 559, 2011 Leg., Reg. Sess. (Cal. 2011).

identical definition to GINA in its own genetic antidiscrimination legislation.¹⁵⁹ Without much case law at the state level, it is difficult to predict where exactly a state like California might fall in its state-protected industries.¹⁶⁰

III. ANALYSIS

Even though only one state currently prohibits the use of genetic information in life insurance underwriting, many states have considered legislation regarding such a ban, and others will likely do so in the future.¹⁶¹ Regardless of whether the path forward is at the state or federal level, Florida's recent passage of House Bill 1189 shows that this is not just a hypothetical situation anymore.¹⁶² The issue presented in *Poore* is not neatly applicable due to the nature of life insurance, because life insurance policies insure against the death of an individual, so only factors that describe that risk would be appropriate to include in underwriting, as opposed to information about an individual's family members.¹⁶³ Thus, genetic information about a spouse would not yield any predictive genetic information about an individual in the life insurance context and is therefore unlikely to be present as an issue here.¹⁶⁴

However, the "two-tiered" or predictive value approach adopted by courts following the *Poore* opinion, such as that used in *Maxwell*, is relevant in the application and underwriting of life insurance policies.¹⁶⁵ If future legislatures were to adopt Florida's ban on life insurers' use of genetic information but continue to utilize GINA's definition of "genetic information," it may be more difficult for life insurance companies to accurately capture risk without violating the statute, making this an unlikely path.¹⁶⁶

Thus, if genetic antidiscrimination proponents want to increase protection at the federal level, there must be some acquiescence to Florida's apparent adoption of the predictive value approach. To demonstrate the importance of amending GINA's definition of

159. *Id.*

160. See generally Tyler Wood, *Genetic Information Discrimination in Public Schools: A Common-Sense Exception*, 49 U. PAC. L. REV. 309, 310 (2018) (applying facts from a key discrimination case in the context of CalGINA to explore the law's scope).

161. See International Genetic Information Policies, *supra* note 35, at 469.

162. FLA. STAT. § 627.4301.

163. International Genetic Information Policies, *supra* note 35, at 465 ("In order for insurers to use a risk factor in underwriting, they must be able to show a correlation between the risk factor and increased cost to the insurer.")

164. See *Poore v. Peterbilt of Bristol, L.L.C.*, 852 F. Supp. 2d 727, 731 (W.D. Va. 2012).

165. See *Maxwell v. Verde Valley Ambulance*, No. CV-13-08044-PCT-BSB, 2014 U.S. Dist. LEXIS 127370, at *1 (D. Ariz. Sept. 11, 2014).

166. See International Genetic Information Policies, *supra* note 35, at 469.

“genetic information” for life insurance specifically, this Article will now use the facts from the *Grisham Farm* and *Maxwell* cases as a framework for exploring the limits of legislation like Florida’s House Bill 1189, which bans the use of certain genetic information by life insurance companies.¹⁶⁷ Despite both of these cases occurring in the employment context, the cases’ underlying facts are easily adapted to the life insurance framework because both plaintiffs were required to disclose information by form to employers.¹⁶⁸ For this analysis, this Article assumes that the life insurance legislation mirrors Florida’s statutory language, except that the definition of “genetic information” will be identical to the definition in GINA.

A. *Comparative Analysis of Both Definitions in the Life Insurance Context Under GINA*

Suppose that a working mother of two applies for a life insurance policy in a state where such a life insurance genetic nondiscrimination statute has been enacted. In the insurance policy application, one of the required questions is whether the woman has “consulted a healthcare provider within the past 24 months, regardless of whether [s]he had been diagnosed with a particular condition, or [sought] advice, diagnosis or treatment from a healthcare provider[.]”¹⁶⁹ In this scenario, the woman has a family history of breast cancer, and she has taken a genetic test where she tested positive for BRCA1 and BRCA2 mutations that indicate that she is at a higher risk for developing breast cancer.¹⁷⁰ However, she has no diagnosis of breast cancer and no precursory conditions that qualify as a manifestation of disease.¹⁷¹

The woman’s answer to this question may reveal her genetic test results and any preventative measures taken against developing breast cancer in the future.¹⁷² For example, if the woman has consulted with her physician about scheduling earlier testing or even

167. See *Grisham Farm Prods.*, 191 F. Supp. 3d at 995; *Maxwell*, 2014 U.S. Dist. LEXIS 127370, at *3–6.

168. *Grisham Farm Prods.*, 191 F. Supp. 3d at 995; *Maxwell*, 2014 U.S. Dist. LEXIS 127370, at *39.

169. *Grisham Farm Prods.*, 191 F. Supp. 3d at 995 (internal quotations omitted).

170. See generally *Can I Lower My Risk of Breast Cancer?*, AM. CANCER SOC., <https://www.cancer.org/cancer/breast-cancer/risk-and-prevention/can-i-lower-my-risk.html> (last visited Feb. 26, 2021).

171. See, e.g., *Atypical Hyperplasia of the Breast*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/atypical-hyperplasia/symptoms-causes/syc-20369773> (last visited Feb. 26, 2021) (listing symptoms and complications).

172. This is consistent with how the *Grisham Farm* court interpreted the employer’s questionnaire with the same question. 191 F. Supp. 3d at 997.

preventative surgery, she would be obligated to disclose such information under the hypothetical form.¹⁷³

If the jurisdiction where this situation occurred adopted the textual definition of “genetic information,” the woman could challenge the form under the strict-liability type approach under GINA (or the hypothetical state law following GINA).¹⁷⁴ The life insurance company would be free to collect information not prohibited by statute. But the company could not collect family history of manifested conditions, genetic test results, or actions relating to those results.¹⁷⁵ This approach robustly protects applicants and insureds because it is a blanket-ban on the collection or solicitation of genetic information.

Even if this jurisdiction chose not to follow the textual definition, the woman would still have recourse for potential discrimination, with one key difference. Under the predictive value approach, courts typically use what Sonia Souter has dubbed the “two-tiered interpretative approach,” where courts may determine whether a family member has a manifested genetic disease and whether the disease was “taken into account” with respect to the individual.¹⁷⁶ With the genetic information limits under GINA’s definition, life insurers are unlikely to require further distillation of the applicant’s own genetic susceptibility to breast cancer without a *physical diagnosis*.¹⁷⁷ Thus, the statute would protect the woman as to her personal genetic test results, but not as to her family history of breast cancer.¹⁷⁸ To be actionable under GINA, as demonstrated in *Poore* and *Maxwell*, the woman would need to prove that her genetic information was “taken into account” with respect to her insurance policy.¹⁷⁹

Suppose a life insurance application required disclosure of a family medical history, as is often the case.¹⁸⁰ In this woman’s situation, she would be obligated to disclose her family history of breast cancer. Maybe her mother died from it or contracted it during her

173. See, e.g., *Grisham Farm Prods.*, 191 F. Supp. 3d at 998.

174. This broad definition of genetic information mirrors what Sonia Souter argues occurs when courts “simply examine whether the information in question falls within the definitional language of GINA.” Souter, *supra* note 6, at 513.

175. FLA. STAT. § 627.4301(2)(b) (“[L]ife insurers . . . may not require or solicit genetic information, use genetic test results, or consider a person’s decisions or actions relating to genetic testing in any manner for any insurance purpose.”).

176. Souter, *supra* note 6, at 508.

177. *Id.*

178. *Id.*

179. See *Maxwell v. Verde Valley Ambulance*, No. CV-13-08044-PCT-BSB, 2014 U.S. Dist. LEXIS 127370, at *48 (D. Ariz. Sept. 11, 2014); *Poore v. Peterbilt of Bristol, L.L.C.*, 852 F. Supp. 2d 727, 731 (N.D. Va. 2012).

180. Rothstein & Brothers, *supra* note 3, at 2100.

lifetime, making the existence of an immediate family member's disease incontrovertible. However, according to the two-tiered approach, the life insurance company would be unable "take into account" whether the applicant would have the *propensity* for the familial disease. The applicant would thus have the same premium as an identical candidate without the family history of breast cancer.

Conversely, to prove malfeasance on the insurer's part with the inclusion of this information, the applicant would need to demonstrate that the insurer did, in fact, take this information into account.¹⁸¹ This puts a high burden on any potential plaintiff to prove that genetic information that was legally obtained was illegally used in the calculation of an insurance premium.¹⁸² Unless a new version of a potential statute shifted the burden to the insurance company to show the policy took no genetic information into account, plaintiffs are essentially out of luck.

Either approach, textual or predictive value, provides too quick of a punishment for life insurers or impracticable lawsuits for insureds or applicants. This makes reform at the federal level difficult without considering a third option.¹⁸³ Legislatures must strike a balance with the interests of applicants and life insurance companies while also being realistic with what exactly "genetic information" means.

B. Why Genetic Antidiscrimination Advocates Should Urge Legislatures to Adopt Florida's Definition in the Life Insurance Context

Both judicial definitions of "genetic information" under GINA in the hypothetical analysis above exclude crucial aspects of risk classification that are very important to the nature of life insurance.¹⁸⁴ Although many advocates in favor of strict genetic antidiscrimination laws include family history as "genetic information," it should be excluded for the purpose of reform.¹⁸⁵ Advocates should clearly signal to legislatures what exactly it is that they want life insurance companies to exclude.

181. See *Maxwell*, 2014 U.S. Dist. LEXIS 127370, at *48.

182. Souter, *supra* note 6, at 511–12 (discussing the *Poore* test and how its holding affects other cases).

183. See *generally* Insurance Risk Classification, *supra* note 7, at 634–38 (discussing the implications of a total ban on genetic information in the insurance context).

184. *Id.*

185. See, e.g., Souter, *supra* note 6, at 511.

This Article argues that advocates should take the position that insurance companies should be prohibited from requiring or inquiring about genetic testing in an application or as part of the disclosure process, while allowing insurers to continue asking applicants questions about family history. Banning genetic testing in the risk classification process for life insurance is a reasonable measure other countries and the state of Florida have taken.¹⁸⁶ Excluding family medical history from “genetic information” allows advocates to focus more on the particularly troubling aspects of life insurers’ use of genetic test results, such as tangible economic harm and stigmatization against individuals with certain genetic traits.¹⁸⁷

This economic harm may affect, for example, those with a predisposition for Alzheimer’s or a genetically-linked cancer, who are denied insurance or offered higher premiums based on genetic test results that indicate propensity for these diseases.¹⁸⁸ Without reform and as genetic testing becomes more affordable, accessible, and advanced, these insurance companies may inadvertently create what Anya Prince refers to as a “genetic underclass.”¹⁸⁹ Denying policies or forcing sky-high costs on individuals because of pre-defined and unchangeable traits is not only unjust, but it echoes an ugly past of eugenics and forced sterilization.¹⁹⁰ Furthermore, allowing genetic testing within these types of insurance policies will harm society by encouraging those with certain genetic conditions to forgo testing needed for treatment or prevention in fear of this discrimination.¹⁹¹ Moreover, this effect reverberates in genetic research, where individuals may decline to participate for the same reasons.¹⁹²

In particular, allowing insurers to utilize family medical history may result in actuarial calculations that can benefit the insured.¹⁹³ For example, not all breast cancers are hereditary; in fact, most are not.¹⁹⁴ Without further knowledge of the applicant’s specific genetic predisposition for this type of cancer, it may be an unpredictable

186. Insurance Risk Classification, *supra* note 7, at 638 (“For example, Austria, France, and Sweden all bar life insurers from using genetic test results in risk classification.”).

187. *See id.* at 636.

188. *Id.*

189. International Genetic Information Policies, *supra* note 35, at 467.

190. Insurance Risk Classification, *supra* note 7, at 636.

191. *Id.*

192. *Id.* at 636–37.

193. *See* Laura Adams, *Life Insurance and Medical History Facts that You Don’t Know*, HUFFPOST (Apr. 28, 2017, 11:37 AM), https://www.huffpost.com/entry/life-insurance-and-medical-history-facts-that-you-dont_b_59035fe4e4b05279d4edbb64.

194. *Genetics*, BREASTCANCER.ORG, <https://www.breastcancer.org/risk/factors/genetics> (last modified Apr. 21, 2021) (“About 5% to 10% of breast cancers are thought to be hereditary, caused by abnormal genes passed from parent to child.”).

statistic for determining whether an applicant is even at risk for a hereditary form of cancer.¹⁹⁵ Including a healthy family history or family history that can be explained by an individual's behavioral choices also benefits the applicant with a potentially lower risk.¹⁹⁶ Not without a downside, the exclusive definition would potentially include conditions such as Huntington's Disease ("HD"), where inheritability from a parent with the condition is fifty percent.¹⁹⁷

However, from the insurer's perspective, if the small number of people who test positive each year for these adult on-set neurodegenerative diseases were to purchase these life insurance policies, this would negatively affect policy holders who have to pay increased premiums to make up for the risk the insurance company takes on with these legal changes.¹⁹⁸ Furthermore, unless the insured's family history has a highly penetrant and fatal disease like HD, family history may not have that much of an impact on a policy holder.¹⁹⁹

Finally, genetic test results yield far more personal information than a family history.²⁰⁰ Because family history is self-reported, it may be of limited value for insurers to rely on to accurately calculate risk.²⁰¹ However, genetic test results can reveal intimate information such as mental illness or incurable disease.²⁰² This is an extreme invasion of privacy that an individual should never be required to disclose.²⁰³ This is especially true considering that the genetic testing that is currently available is "remarkably unpredictable" and varies in relevance for risk classification.²⁰⁴ Thus, to ensure privacy to the individual and prevent economic and social harms based on immutable traits, removing family history from "genetic information" in the context of life insurance is the best path

195. See Insurance Risk Classification, *supra* note 7, at 657 (discussing penetrance estimates among various genetic conditions).

196. See Adams, *supra* note 193 ("Insurers will look at how much a family history of cancer can be attributed to genetics and how much to lifestyle choices. For instance, if your mother developed lung cancer because she smoked a pack of cigarettes a day, your insurer might not ding you if you are a non-smoker.")

197. Insurance Risk Classification, *supra* note 7, at 655–56.

198. *Id.*

199. *Id.* at 655 ("Family history, however, is a notoriously inaccurate and imprecise risk prediction tool due, in part, to patients' potentially incomplete knowledge or misunderstanding of diagnoses.")

200. See generally *id.* at 636 ("[G]enetic tests have the potential to disclose highly personal information about one's self and family, such as a predisposition to a mental illness or an incurable, degenerative disease.")

201. *Id.* at 655.

202. *Id.* at 636.

203. *Id.*

204. *Id.* at 655–56.

forward to achieve change in genetic antidiscrimination laws at the legislative level.

IV. CONCLUSION

With the innovative field of genomics, the healthcare profession has increased access and improved outcomes of detecting and treating various genetic conditions. However, these great achievements must not become overshadowed by the misuse of information about personal, immutable characteristics in industries such as life insurance. Banning life insurance companies from requiring genetic testing in an application or as part of the disclosure process is the best balance to strike between protecting insureds while still considering the insurance companies' function.

Continuing to include questions about family history gives insurers a way to calculate some risk without worrying about strict liability under a GINA-like law and without having the data to discriminate based on extremely personal and unchangeable genetic information. Florida has shown that this is a path forward where this compromise is available, and other states and Congress should consider making a similar change to continue to protect against genetic discrimination.