



Special section: GINA at 10 years

GINA at 10 years: the battle over ‘genetic information’ continues in court

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ABSTRACT

Ten years ago, the Genetic Information Nondiscrimination Act (‘GINA’) came into law. While it was unclear how prevalent genetic discrimination was, GINA was enacted preemptively to prevent discrimination in insurance and employment. It also created uniform protections to remedy a confusing patchwork of state and federal protections. Finally, Congress hoped GINA would allay public fears of genetic discrimination that discouraged people from undergoing genetic testing and participating in genetics research. To address those fears, Congress enacted robust protections against genetic discrimination in health insurance and employment, in part, by defining ‘genetic information’ as broadly as possible.

Over the last ten years, however, the courts have been battling over the meaning of ‘genetic information’. One interpretive approach adheres strictly to GINA’s statutory language; the second interprets the definition restrictively and contrary to the plain meaning of GINA and its underlying goals. While this interpretive conflict demonstrates the difficulty of distinguishing genetic information from non-medical information, this article argues for the broader interpretation. Such an interpretation reflects Congress’s choice among imperfect definitional options and it furthers the goal of creating strong protections in health insurance and employment. Finally, definitional consistency is necessary to achieve uniform protections against genetic discrimination.

KEYWORDS: genetic and genomic testing, genetic discrimination

If you took a genetic test and learned that you faced an increased risk of breast or ovarian cancer, could you be denied employment opportunities based on that risk? Could your employer even ask about or obtain such information? It would not surprise many people to learn that because of a federal law—the Genetic Information Nondiscrimination Act (‘GINA’)¹—the answer to these questions is ‘no’.

But what about information regarding the health of your family members? What if your parent had been diagnosed with AIDS or your spouse had developed multiple sclerosis? Does GINA prohibit your employer from obtaining or using such information to make employment decisions? Does such information have anything to do with genetic discrimination? One might imagine, at first glance, that GINA does not, and perhaps should not, apply to such information. Indeed, some courts have so ruled. This article argues, however, that GINA extended its protections to such scenarios through its broad definition of ‘genetic information’, and that doing so is consistent with Congress’s goal of preventing genetic discrimination.

GINA was signed into law 10 years ago by President Bush after Congress passed it by ‘a near-unanimous vote’.² The legislation was viewed as a real victory in bringing about federal protections against genetic discrimination. Senator Ted Kennedy, for example, hailed GINA as the ‘first civil rights bill of the new century of the life sciences’.³ The passage of this legislation was no small task. It represented the culmination of 13 years of efforts that began in 1995 when the late Congresswoman Louise Slaughter (D-NY) and Senator Olympia Snowe (R-ME) introduced the first federal legislation limiting genetic discrimination.⁴ While the original bill focused only on health insurance discrimination, variations introduced in each subsequent Congress ultimately expanded the scope of protection to include employment discrimination. Although these legislative efforts received bipartisan support in both the House and Senate, inaction in the House prevented its becoming law for over a decade. Finally, by a vote of 414–1 and 95–0, respectively, the House and Senate passed GINA, and it was signed into law on May 21, 2008.⁵

The story of why GINA was enacted is complex, involving a sometimes surprising mix of bedfellows: not only the expected patient advocates, consumer groups, medical profession, and researchers, but also ‘the medical products industry and pharmaceutical companies’.⁶ The obvious rationale for such legislation was to prevent genetic discrimination.⁷ But as scholars have pointed out, GINA was unusual in legislating against

¹ Pub. L. No. 110–233, 122 Stat. 881 (2008) (codified in scattered sections of 26, 29, and 42 U.S.C.).

² Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 599 (2011) [hereinafter Roberts, GINA].

³ Meredith Wadman, *Banning Genetic Discrimination*, NATURE, Apr. 25, 2008, <https://www.nature.com/news/2008/080425/full/news.2008.780.html> (last visited Feb. 17, 2019).

⁴ *Legislative History of GINA*, NAT’L HUMAN GENOME RESEARCH INST. (Apr. 17, 2017), <https://www.genome.gov/27568535/legislative-history-of-gina/> (last visited Dec. 11, 2018).

⁵ *Id.*

⁶ 154 CONG. REC. E784-03 (daily ed. Apr. 30, 2008) (statement of Rep. Lee), 154 Cong. Rec. E784-03, at *1901654 (Westlaw).

⁷ Pub. L. No. 110–233, § 2(1) (noting that scientific advances in human genetics ‘give rise to the potential misuse of genetic information to discriminate in health insurance and employment’).

a form of discrimination that had not historically been problematic or pervasive.⁸ In contrast, Title I of the American with Disabilities Act (“ADA”) and Title VII of the Civil Rights Act of 1964 were enacted to counter a history of discrimination based on, respectively, disability and sex, race, color, national origin, or religion.⁹ In other words, GINA was preemptive, intended to prevent genetic discrimination from ever becoming a problem.¹⁰

Major advances in genetics research, such as the federal funding in 1990 of the Human Genome Project (“HGP”), stoked concerns about genetic discrimination. The federal government planned to invest \$3 billion to decode the full sequence of the 3 billion base-pair human genome and to identify all of its genes.¹¹ In ‘herald[ing] the “genomic age”’,¹² the HGP and other genetics research were intended to expand our ability to identify genetic risks and understand the role of genetics in disease. While such information promised to improve preventive and precision medicine, it reinforced a growing propensity to understand and explain human illness and traits in genetics terms, perpetuating the allure of genetics determinism—the idea that our ‘genes determine and explain everything about us’.¹³ Such attitudes heightened worries among scholars and legislators that employers and insurers would increasingly find genetic information useful in predicting the health risk of individuals and perhaps even define them according to their genetic make-up. In other words, it threatened genetic discrimination.

Although some studies in the early 1990s purported to demonstrate that genetic discrimination was already a great problem,¹⁴ the evidence was largely equivocal. Instead, there were many reasons to believe that genetic discrimination was not a significant issue—at least, not yet.¹⁵ Nevertheless, the reports of these studies and endless references to the risk of genetic discrimination in media accounts of genetic discoveries¹⁶ persuaded the public that genetic discrimination was a serious concern. Even if not grounded in strong evidence of existing discrimination, these worries

⁸ Bradley A. Areheart, *GINA, Privacy, and Antisubordination*, 46 GA. L. REV. 705, 707 (2012) (describing GINA as ‘more forward-looking and less responsive to serious social harms’ because ‘only a few cases of genetic discrimination have been documented’); Roberts, *GINA*, *supra* note 2, at 600.

⁹ Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 457–59, 461–62 (2010) [hereinafter, Roberts *Preempting*].

¹⁰ *Id.* at 441, 462–63. The congressional findings for GINA did describe, however, the history of abuses on the basis of genetics in the deeply problematic eugenics era, Pub. L. No. 110–233, § 2(2), and stigmatization and discrimination against African-American based on genetic traits, *Id.* § 2(3), which in combination with ‘the current explosion in the science of genetics . . . compels Congressional action in this area’, *Id.* § 2(2).

¹¹ *The Human Genome Project Completion: Frequently Asked Questions*, NAT’L HUMAN GENOME RESEARCH INST. <https://www.genome.gov/11006943/human-genome-project-completion-frequently-asked-questions/> (noting that ultimately the federal government only paid \$2.7 billion dollars and was completed in 2003, two years in advance of its projected end date) (last visited Dec. 11, 2018).

¹² Ifeoma Ajunwa, *Genetic Data and Civil Rights*, 51 HARV. C.R.-C.L. L. REV. 75, 85 (2016).

¹³ Sonia M. Suter, *The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?*, 79 WASH. U. L. Q. 669, 674–75 (2001); see also Ajunwa, *supra* note 12, at 85–87.

¹⁴ See eg Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENET. 476 (1992); E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621 (1996).

¹⁵ See Mark A. Hall, *Legal Rules and Industry Norms: The Impact of Laws Restricting Health Insurers’ Use of Genetic Information*, 40 JURIMETRICS 93 (1999) (noting that ‘genetic discrimination by health insurers [was] very low or nonexistent, both before [state genetic-specific antidiscrimination laws] were enacted and afterwards’).

¹⁶ Suter, *supra* note 13, at 678–82 (noting that these media accounts frequently follow a formula of first describing the promise of these advances and then detailing the perils of discrimination they threaten).

resulted in behavior that researchers and health care providers found troubling: many individuals were reluctant to avail themselves of new genetic tests for their own health care or to participate in genetics research.¹⁷

Two sets of concerns, therefore, were the impetus for genetic nondiscrimination legislation at the state and federal levels: worries about the potential for actual genetic discrimination and apprehension about the public health and research implications of public fears of genetic discrimination (whether or not genetic discrimination was prevalent). States began to enact genetic-specific legislation in the 1990s with a focus primarily on preventing discrimination in the context of health insurance and employment.¹⁸ The challenge, however, was that state laws differed in various respects—whether they prohibited genetic discrimination at all and, if so, what uses of genetic information they proscribed and how they defined ‘genetic information’.¹⁹ Further, although the Health Insurance Portability and Accountability Act (“HIPAA”) (unbeknownst to many) prohibited genetic discrimination against individuals in employer-sponsored group health plans,²⁰ it did not provide full protections.²¹ As a result, until GINA was enacted, legislation prohibiting genetic discrimination at the state and federal level was ‘incomplete in both the scope and depth of its protections’.²²

Thus, the motivation behind GINA was more than just preemptive. It was also geared at remedying ‘the patchwork of State and Federal laws’, which the public found ‘confusing and inadequate to protect them from discrimination’.²³ But most significantly, by developing a ‘uniform basic standard’ at the federal level ‘to fully protect the public from discrimination’, the goal of GINA was to ‘allay [public] concerns about the potential for discrimination’ so individuals would take advantage of genetic testing and new therapies as well as participate in genomics research.²⁴

By limiting its focus on health insurance and employment, however, GINA did not entirely deliver on its promise ‘to fully protect the public from discrimination’.²⁵ The risks of genetic discrimination are arguably as great, if not greater, with respect to other lines of insurance such as life, disability, or long-term care insurance. Nevertheless, lobbying efforts within those industries and a sense that health insurance differs in important ways from other forms of insurance contributed to nondiscrimination

¹⁷ Roberts *GINA*, *supra* note 2, at 603–06.

¹⁸ ‘Prior to enactment of GINA, 34 states and the District of Columbia had promulgated their own genetic discrimination laws’. Stephen E. Trimboli & Marissa B. Ruggiero, *Navigating the Genetic Information Nondiscrimination Act of 2008*, FED. LAWYER, Nov./Dec. 2011, at 26.

¹⁹ See Suter, *supra* note 13, at 690–96; *Table of State Statutes Related to Genomics*, NAT’L HUMAN GENOME RESEARCH INST. <https://www.genome.gov/27552194/> (last visited Jun. 1, 2018).

²⁰ 29 U.S.C. §§ 1181–82 (2006), 42 U.S.C. §§ 300gg-41 (2006) (prohibiting the use of genetic information to determine eligibility or set premiums or the treatment of genetic information as a preexisting condition).

²¹ For example, it did not prevent discrimination of the group, did not prohibit insurers from seeking genetic information or requiring genetic tests, and it did not apply to individual health insurance policies or non-employer group plans. See Roberts, *Preempting*, *supra* note 9, at 443–44; LORI B. ANDREWS ET AL., GENETICS: ETHICS, LAW AND POLICY 720 (4th ed. 2015).

²² Pub. L. No. 110–233, § 2(5).

²³ *Id.*

²⁴ *Id.*

²⁵ *Id.* (emphasis added).

protections that focused only on health insurance and employment at the federal level and in many states.²⁶

An additional challenge that Congress faced in drafting GINA was deciding how to define ‘genetic information’, a problem with which state legislatures had also grappled in drafting their own genetics legislation. Many state laws define ‘genetic information’ narrowly as the result of genetic tests or sometimes a bit more broadly as the result of genetic tests of family members.²⁷ Advocates of genetic antidiscrimination laws, however, criticized these definitions as inadequate because genetic information can be obtained not merely from the result of genetic tests, but also from family history. In an effort to protect the public ‘fully’ against genetic discrimination, therefore, Congress defined ‘genetic information’ broadly to include family history.

Congress’s definitional task was not simple. As I describe in Part III, attempting to distinguish genetic information from other medical information is conceptually fraught because there are no bright lines between what is genetic or non-genetic medical information; the real distinction is the degree to which genetics or environment play a role. Additionally, many understandings of genetic discrimination are limited to discrimination based on predisposition to, as opposed to actual manifestation of, disease. Indeed, in the debates over how to define ‘genetic information’ in GINA, some legislators criticized the proposed broad definition as failing to reflect the primary goal of GINA: to ‘combat[] discrimination based on one’s *propensity* for disease’.²⁸ Clearly concerned that too narrow a definition would not adequately or fully protect against genetic discrimination (and in spite of the objections), Congress adopted the proposed definition—arguably one of the broadest legislative definitions of genetic information.²⁹

In the last 10 years, however, the courts have been divided over how to interpret GINA’s definition of ‘genetic information’, reflecting the legislative debate within Congress about the appropriate breadth of the term. The result is two different conceptions of what constitutes ‘genetic information’ under GINA. One adheres strictly

²⁶ See Turna Ray, *After GINA, Where Do Life Insurance Firms Stand on Using Genomic Information for Coverage Decisions*, GENOMEWEB, Mar. 3, 2010, <https://www.genomeweb.com/dxpgx/after-gina-where-do-life-insurance-firms-stand-using-genomic-information-coverage#.XA.8ZmhKg2w> (noting ‘the prevailing view among payors that health insurance is different in scope and societal function from life insurance, since the former grants individual access to health services by reimbursing doctors, hospitals, and pharmacies, and the latter provides financial protection to individuals and their families’) (last visited Jun. 1, 2018); 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/> (noting that although early bills included protections against discrimination in coverage for life insurance, long-term care, and disability, the ‘political calculation was made that health insurance and employment were where the arguments were strongest and the support was strongest’) (quoting Jeremy Gruber, GINA advocate and former president of the Council for Responsible Genetics) (last visited Jun. 1, 2018).

²⁷ Suter, *supra* note 13, at 691, Table 1 & 702.

²⁸ *Lowe v. Atlas Logistics Group Retail Services (Atlanta)*, L.L.C., 102 F. Supp. 3d 1360, 1367–68 (N. D. Ga. 2015) (describing the late Representative Louise Slaughter’s discussions of examples of how GINA would protect individuals when genetic tests revealed they were at increased risk of certain diseases) (emphasis added).

²⁹ See Mark A. Rothstein et al., *Limiting Occupational Medical Evaluations Under the American with Disabilities Act and the Genetic Information Nondiscrimination Act*, 41 AM. J. L. & MED. 523, 550 n.187 (noting that of 35 state statutes prohibiting employment discrimination, only 4 included family history in protected genetic information).

to the statutory language and broad definition; the second narrows the definition in light of GINA's goals to protect against discrimination based on information predictive of future disease.³⁰ While on first glance, the second approach might seem appropriate given that genetic discrimination is often defined as propensity for disease, this article critiques such a reading of GINA as deviating from the plain language of the statute and inconsistent with Congress' explicit efforts to define genetic information broadly. Given the impossibility of defining genetic information precisely because of the spectrum of heritability of medical conditions and the lack of a clear line between what is definitively inheritable and what is not,³¹ Congress opted for a definition that would be fully inclusive of information that could be used to determine propensity to disease. That such a definition might be overbroad on occasion was presumably the price Congress was willing to pay to protect against genetic discrimination.

This article begins in Part I by briefly describing GINA and the scope of its protections. Part II details the contrasting judicial interpretations of GINA with respect to genetic information. Part III critiques the narrower approach, arguing that it is not only inconsistent with the plain meaning of the text of GINA, but in subtle and less subtle ways, it deviates from the underlying goals of the statute to define genetic information broadly and to develop bright-line rules for enforcement and compliance purposes. The piece ends by noting that the conflicting interpretive approaches reflect the difficulties of trying to distinguish genetic information from non-medical information. The challenge of this task highlights the conceptual problems of singling out protections for just genetic information. As a result, it ends by offering suggestions for how some of GINA's protections might be broadened beyond genetic information. Congress, however, decided to address genetic discrimination, a goal that had considerable political support. In doing so, it made a particular definitional choice among imperfect options. The courts should not undo those efforts simply because they would have made a different choice had they drafted the legislation themselves. As long as we have genetic-specific legislation, we must achieve consistency in its application.

I. OVERVIEW OF GINA

GINA comprises three titles. The two main parts are Title I, which prohibits genetic discrimination with respect to health insurance, and Title II, which bans genetic discrimination in employment.³² Title I amends various federal laws to prohibit genetic discrimination by all forms of health insurance providers, including employer-sponsored group health plans and health insurance issuers providing group health insurance³³ or individual health coverage.³⁴ It protects against health insurance discrimination by proscribing various discriminatory *uses of* genetic information. For example, GINA prohibits decisions about premium rates or contribution rates for group

³⁰ See *infra* Part II.A.

³¹ Suter, *supra* note 13, at 701–02.

³² Title III contains miscellaneous provisions, including severability provisions, Pub. L. No. 110–233, § 301, and child labor provisions, *Id.* § 302.

³³ *Id.* § 101 (amending the Employment Retirement Security Act of 1974).

³⁴ *Id.* § 102 (amending the Public Health Service Act). It also applies to 'Medigap insurance and state and local federal governmental plans'. Trimboli & Ruggiero, *supra* note 18, at 24.

health plans based on genetic information regarding an individual in the group.³⁵ Because the HIPAA already prohibited the use of genetic information to determine eligibility or set premiums and the treatment of genetic information as a preexisting condition for employer-sponsored group health plans,³⁶ GINA fortified protections with respect to group plans by prohibiting discrimination of groups in their entirety and including non-employer group plans in these protections.³⁷

'GINA's main value', however, was its protection with respect to the individual insurance market, for which there had been no federal protection and only a patchwork of protection at the state level.³⁸ Under GINA, health insurers that offered coverage in the individual market could no longer establish eligibility, set premium rates, or impose preexisting condition exclusions based on genetic information.³⁹ Of course once the Patient Protection and Affordable Care Act of 2010 ('ACA')⁴⁰ became law two years after GINA was enacted, it imposed significant reforms to private health insurance, many of which overlap with the protections under Title I of GINA.⁴¹

An additional federal protection with respect to insurance offered through individual or group plans was Title I's prohibitions of insurer *access to* genetic information. Thus, health plans or health insurance issuers of group or individual health insurance may not request or require individuals or their family members to undergo a genetic test. Nor may they request, require, or purchase an individual's genetic information for underwriting or enrollment purposes.⁴²

Like Title I, Title II prohibits genetic discrimination by proscribing discriminatory *uses of* genetic information. The difference, of course, is that the prohibitions in Title II apply to employment decisions based on genetic information, such as hiring; discharging; determining compensation, terms, conditions, and privileges of employment⁴³; or limiting, segregating, or classifying an employee in ways that could deprive the

³⁵ Protections against eligibility decisions for group health plans based on genetic information were already prohibited under HIPAA. See *supra* text accompanying note 20.

³⁶ 29 U.S.C. §§ 1181–82 (2006), 42 U.S.C. §§ 300gg-41 (2006).

³⁷ Pub. L. No. 110–233, § 101 (amending the Employee Retirement Income Security Act of 1974); *Id.* § 102 (amending the Public Health Services Act); *Id.* § 103 (amending the Internal Revenue Code).

³⁸ Mark A. Rothstein, *GINA's Beauty is Only Skin Deep*, 22 GENE WATCH No. 2 at 9 (Apr.–May 2009) [hereinafter Rothstein, *Skin Deep*], <http://www.councilforresponsiblegenetics.org/GeneWatch/GeneWatchPage.aspx?pageId=184>

³⁹ Pub. L. No. 110–233, § 2753(a)–(c).

⁴⁰ Pub. L. No. 111–148, as modified by the Health Care and Education Reconciliation Act, Pub. L. No. 111–152.

⁴¹ AMANDA K. SARATA ET AL., CONG. RESEARCH SERV., R41314, THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 AND THE PATIENT PROTECTION AND AFFORDABLE CARE ACT OF 2010: OVERVIEW AND LEGAL ANALYSIS OF POTENTIAL INTERACTIONS 5–6 (2011). For example, 'under GINA, a group health plan and a health insurance issuer may not adjust premium or contribution amounts on the basis of genetic information', and under 'the ACA, certain health insurance issuers may only vary premiums based on certain specified factors (i.e., tobacco use, age, geographic area, and self-only or family enrollment)'. *Id.* at 5. '[T]hese provisions of the ACA and GINA are not identical in scope', however. *Id.* For example, the ACA 'limitations on premium amounts . . . apply only to health insurance issuers in the individual and small group markets', whereas such limitations under GINA also apply 'to self-insured group health plans or insurers in the large group market'. *Id.* Moreover, 'this section of the ACA applies only to premium rates, whereas GINA applies to premiums as well as contribution amounts'. *Id.*

⁴² Pub. L. No. 110–233, §§ 101–106; see also SARATA ET AL., *supra* note 41, at 3–4.

⁴³ Pub. L. No. 110–233, § 202(a).

employee of employment opportunities or ‘adversely affect the status of the employee’ based on genetic information.⁴⁴

In addition, GINA also proscribes employers from *acquiring* genetic information. As some scholars have noted, this reflects a privacy protection that is distinct from, but that can also bolster, the antidiscrimination features of GINA.⁴⁵ Because it can be difficult to prove that employment decisions are based on genetic discrimination, this provision prevents employers from obtaining information that they may be tempted to use for discriminatory purposes, and it eliminates the burden of trying to establish whether access to genetic information played a role in adverse employment decisions. Thus, under GINA, employers may not ‘request, require, or purchase’ an employee’s genetic information with a few exceptions.⁴⁶

As noted in the introduction, a significant issue in drafting GINA was the definition of ‘genetic information’. It is worth noting that Congress made no distinctions in its definitions with respect to the privacy or antidiscrimination provisions of GINA, suggesting that although these provisions address distinct interests, they are interrelated. Although there was some disagreement in the floor debates,⁴⁷ Congress ultimately chose a very broad definition, which recognizes that genetic information can exist in many forms: the result of genetic tests of an individual or an individual’s family members, the presence of disease in family members (ie family history), as well as the request or receipt of genetic services and participation in clinical research by the individual or family member. Thus, both Title I and Title II define an individual’s ‘genetic information’ as ‘information about (i) such 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’.⁴⁸

This definition includes what most people think of as genetic information: the results of genetic tests. GINA defines genetic tests not only as ‘an analysis of human DNA, RNA, chromosomes’, but also as analysis of ‘proteins or metabolites that detects genotypes, mutations, or chromosomal changes’,⁴⁹ recognizing that genetic risks can sometimes be detected indirectly through analysis of molecules other than DNA, RNA, or chromosomes. GINA also adopts the broader conception of genetic information: family history, which includes not only genetic tests of family members, but also the manifestation of disease or disorder in family members. This broad definition recognizes that important genetic information can exist, for example, if family members have

⁴⁴ *Id.* § 202(b).

⁴⁵ See *infra* note 181 and accompanying text.

⁴⁶ The exceptions include inadvertent requests, as part of a wellness program where the employee voluntarily provides such information and the employer only receives information ‘in aggregate terms that do not disclose the identity of specific employees’, and when the employer requests family medical history to comply with Family and Medical Leave Act certification. *Id.* § 202(b) (1)–(5) (also excepting instances ‘where the employer purchases documents that are commercially or publicly available’ and instances of ‘genetic monitoring of the biological effects of toxic substances in the workplace’ if among other things the testing is voluntary and the employer receive results ‘only in aggregate terms that do not disclose the identity of specific employees’).

⁴⁷ See *supra* text accompanying note 28 and *infra* text accompanying notes 154–163, 173.

⁴⁸ Pub. L. No. 110–233, § 101(d), 102(a)(1)(B), 103(d), 104(b), 201(4)(A)(i)–(iii); 42 U.S.C. § 2000ff(A)(i)–(iii).

⁴⁹ Pub. L. No. 110–233, §§ 101(d), 102(a)(1)(B), 103(a)(2), 104(b), 201(7).

been diagnosed with a genetic condition like Huntington's disease or even less fully penetrant heritable conditions, like breast or ovarian cancer.⁵⁰

Perhaps because the line between genetic information and non-genetic information is somewhat blurry, however, Congress did not make distinctions between medical diagnoses in family members that are explicitly defined as genetic diseases. Congress could have modified or limited the kind of family history that would be considered genetic information. For example, it might have defined family history as the 'manifestation of an *inheritable* disease or disorder in the family members'. Notably, however, GINA's definition of family history does not modify the nature of disease or disorder in a family member in such a manner.⁵¹ The definition extends even further by including 'any request for, or receipt of, genetic services, or participation in clinical research, which includes genetic services' by the individual or her family member,⁵² whether or not the family member is ultimately found to have a heritable genetic condition. The resulting definition of genetic information, therefore, is not only broad in including family history, but also broad in its conception of family history. Such an expansive definition includes family history, even if it is not necessarily predictive of an employee's disease propensity.

Despite defining genetic information broadly, Congress limited the scope of protections against genetic discrimination in two key ways. First, GINA does not address areas where genetic discrimination may be more likely, such as in the context of life, long-term care, or disability insurance.⁵³ There is little in the legislative history to explain this decision, although, as noted earlier, it is likely a consequence of limited political will and lobbying on the part of the insurance industries to limit GINA's protections to health insurance.⁵⁴ Second, it provides no protections for symptomatic individuals. Title I's prohibition against insurance discrimination does not preclude insurers from making health insurance decisions 'based on the *manifestation* of a disease or disorder of an individual'.⁵⁵ Similarly, Title II explicitly distinguishes genetic information from information about manifested genetic conditions, stating that GINA does not prohibit employers or covered entities from using, acquiring, or disclosing 'medical information that is not genetic information about a manifested disease, disorder, or pathological condition of an employee or member, *including a manifested disease, disorder, or pathological condition that has or may have a genetic basis*'.⁵⁶ Once a genetic risk develops into

⁵⁰ See Morse Hyun-Myung Tan, *Advancing Civil Rights, the Next Generation: The Genetic Information Nondiscrimination Act of 2008 and Beyond*, 19 HEALTH MATRIX 63, 67 (describing cases reports where discrimination was based on such information).

⁵¹ See *infra* text accompanying notes 175–176.

⁵² 42 U.S.C.A. § 2000ff (4) (B). The definition, however, excluded 'information about the sex or age of any individual'. *Id.* § 2000ff (4) (C).

⁵³ Rothstein, *Skin Deep*, *supra* note 38, at 9 (noting that GINA also 'does nothing to prohibit discrimination in ... mortgages, commercial transactions, or any other possible uses of genetic information').

⁵⁴ See *supra* note 26 and accompanying text.

⁵⁵ Pub. L. No. 110–233, § 101(a)(3); 29 U.S.C.A. § 1182 (emphasis added) (noting that GINA does not preclude insurers 'offering health insurance coverage in connection with a group health plan' from increasing the premium for an employer on that basis); Pub. L. No. 110–233, § 102(a)(3); 42 U.S.C.A. § 300gg–1 (same); Pub. L. No. 110–233, § 2753 (a)(2), (b)(2), & (c)(2); 42 U.S.C.A. § 300gg–52 (noting that GINA does not preclude insurers 'from establishing rules for eligibility for an individual to enroll in individual health insurance coverage', 'adjusting premium or contribution amounts for an individual', or 'imposing any preexisting condition exclusion for an individual with respect to health insurance coverage' on that basis).

⁵⁶ Pub. L. No. 110–233, § 210; 42 U.S.C. § 2000ff-9 (emphasis added).

a manifested condition, GINA no longer applies. At that point, any federal protection against health insurance and employment discrimination depends on, respectively, the ACA and the American with Disabilities Act ('ADA').⁵⁷ In making clear that medical information about a *manifested* genetic (or non-genetic) condition in an individual is not 'genetic information' about that individual, Congress narrowed the definition of 'genetic information' in this respect considerably.⁵⁸

GINA's distinction between 'manifested' genetic disease and genetic risk reflects the view of many that genetic discrimination is problematic when it is based on *presymptomatic* genetic information, ie information about genetic risks before the condition develops.⁵⁹ The concern is that people might be denied access to insurance or employment based on a potential risk of illness that may never manifest or may only develop years later. Many find this deeply problematic because genetic inheritance is immutable and beyond our control.⁶⁰ In addition, presymptomatic genetic information is viewed as deeply private, not only because it is personal, sensitive, and potentially stigmatizing, but also because it can be hidden from others, and even from ourselves, before the disease develops, if it ever will.⁶¹

As we shall see in Part II, one strand of case law relies on GINA's focus on presymptomatic genetic discrimination to interpret 'genetic information' based on whether the information at issue, including family history, is predictive of disease risk. While this narrow interpretation may initially seem appealing and consistent with the goals of Congress, as Part III argues in more detail, it is problematic for several reasons. First, it goes against the unambiguous statutory language of GINA and it defeats Congress' goal of trying to provide full protection of genetic information. While Congress enacted GINA because of a concern for discrimination based on predisposition, the broad definition reflects a recognition of the impossibility of drawing a bright line between clearly inheritable diseases and those that are not inheritable. Since any definition will inevitably be either overbroad or too narrow, Congress seemed quite willing to err on the side of breadth over narrowness in defining family history.

Second, any definition that attempts to define 'genetic information' in terms of its ability to identify a propensity for disease raises difficult enforcement and compliance

⁵⁷ As Mark Rothstein has pointed out, however, some individuals may find themselves protected by neither GINA nor the ADA. Someone with evidence of the early stages of illness from 'sensitive biomarkers and sophisticated analyses of endotypes' would not be protected under the ADA because its protections are limited to severely affected individuals. But because GINA does not define 'a manifested disease, disorder, or pathological condition', it is not clear whether such an individual would be presymptomatic and protected under GINA or affected by a manifested disease and not protected under GINA. Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J. L. MED & ETHICS, 837, 838–39 (2008) [hereinafter Rothstein, *GINA*].

⁵⁸ Before the ACA was enacted, this approach led to inequities in protections against genetic discrimination depending on whether someone was at risk for a genetic condition, for which GINA and related state laws offered protections, or had developed the genetic condition, in which case GINA would not prohibit insurance discrimination. See Suter, *supra* note 13, at 715–21; Rothstein *supra* note 57, at 837.

⁵⁹ See eg Hall, *supra* note 15, at 97.

⁶⁰ Suter, *supra* note 13, at 706–07.

⁶¹ *Id.* at 708–09. As I have argued before and shall discuss at greater length in Part III, the line between presymptomatic and symptomatic genetic information raises other justice issues. *Id.* at 715–21 (describing the inequities of protecting against health insurance discrimination for individuals who have presymptomatic genetic risks when no such protections exist for those with symptomatic genetic diseases whose need for insurance is especially because of the development of disease).

problems for the EEOC and covered entities, respectively. Neither is well positioned to make medical judgements as to how predictive such information is of future health risks. Even within medicine, our understanding of genetics and patterns of inheritance is continually evolving.

Third, the (sometimes over-inclusive) definition of ‘genetic information’ that Congress adopted does not require analysis of the employer’s perceptions or beliefs about the predictive value of the information. Given the challenges of demonstrating discriminatory intent, GINA claims would be even harder to bring if employees would have to demonstrate the employer’s state of mind with respect to whether they viewed family history as genetic information or not.

Finally, Congress may have been concerned about discrimination based on an employer’s desires to avoid high health care costs of family members. While an employee’s health care costs might also be a concern, the ADA provides protections against discrimination based on manifested illnesses that constitute a disability, and GINA provides protections against discrimination based on genetic predisposition to disease. But the ADA does not protect against discrimination based on the health care costs of family members. Congress may not, therefore, have been too troubled by a definition of ‘genetic information’ that was not limited to family histories of *inheritable* genetic conditions, but included all family histories. Such a definition protects against employment discrimination either because the family history reveals a genetic risk in an employee or because of the family history presents cost concerns unrelated to an employee’s risk of disease or qualifications for the job. We turn now to an exploration of the development of this case law before exploring in more detail the rationales for adopting the broader definition in Part III.

II. HOW THE COURTS INTERPRET ‘GENETIC INFORMATION’ UNDER GINA

Although GINA was enacted 10 years ago, not many cases have dealt with GINA on a substantive level. Perhaps because the ACA’s health insurance reforms overlap with many of the protections of Title I, GINA case law primarily concerns employment discrimination claims brought under Title II.⁶² Often, GINA claims seem to be an afterthought, raised only after the plaintiff has alleged every other possible employment discrimination claim. As a result, a good many GINA claims have no colorable basis at all.⁶³ Nevertheless, a growing number of GINA employment claims do raise substantive issues and provide some insight into the judiciary’s understanding of GINA.

The case law addresses two types of employment claims under GINA: 1) allegations that the employer made discriminatory employment decisions based on genetic information, and/or 2) allegations that the employer improperly acquired genetic information. Given that the latter is easier to establish than the former, it is not surprising

⁶² Cf. Roberts, *GINA*, *supra* note 2, at 634.

⁶³ Brad Areheart presented his findings about GINA litigation at The Genetic Information Non-Discrimination Act (GINA) at 10 Years, 112th AALS Annual Meeting (Jan. 5, 2018). He found 198 cases that mention GINA, but only roughly 100 have orders dealing with GINA. Approximately 40% of those cases involve ‘overclaiming strategies’ where every discrimination claim in the books is raised. Of the 60 cases that remained a number either lacked facts to support the claim, were procedurally or time barred, or were resolved on other grounds. He found no more than 16 cases that addressed substantive features of GINA. *Id.*

that many GINA cases only concern assertions of improper acquisition of genetic information. Either kind of claim, however, requires the court to examine whether the information allegedly used for discriminatory purposes or allegedly acquired improperly constitutes ‘genetic information’, which is defined identically for both types of claims. Some of these cases were easily resolved in favor of the employer because the medical information concerned an individual’s manifested condition, which is expressly distinguished from genetic information.⁶⁴ The information at issue in the remaining cases primarily concerns information about the health of family members; in one instance, it concerns information from genetic analysis that does not explicitly assess disease risk.

As we shall see, courts have taken two approaches to determine whether information at issue in GINA cases constitutes ‘genetic information’. The first approach, established by *Poore v Peterbilt of Bristol, L.L.C.*⁶⁵ and followed by a few other courts, construes genetic information narrowly and arguably contrary to explicit statutory language. The second approach construes genetic information broadly and in a manner consistent with both the goal of GINA and the statutory language. We begin with the first approach.

II.A. The Narrow Interpretation of ‘Genetic Information’

Poore v Peterbilt Bristol, L.L.C., which was decided in 2012, was the first published case to address the question of whether medical information, other than information about an individual’s manifested condition, constitutes genetic information under GINA. The employee, Mark Poore, worked for Peterbilt of Bristol, L.L.C. (‘Peterbilt’), which provided health insurance for Poore and his family. In responding to his employer’s ‘health insurance questionnaire regarding his family’s general medical conditions and medications’,⁶⁶ Poore indicated that his wife had been diagnosed with multiple sclerosis. Three days later, despite ‘no complaints about [his] work performance’, Poore was terminated from his position ‘without sufficient explanation’.⁶⁷

Poore brought a number of employment discrimination claims against Peterbilt, including one alleging discrimination based on his employer’s acquisition of genetic information in violation of GINA.⁶⁸ In a brief opinion, the court found that the information at issue—the wife’s multiple sclerosis diagnosis—was not ‘genetic information’ with respect to Poore, and therefore it dismissed the GINA discrimination claim.⁶⁹

To reach this conclusion, the court turned to GINA’s legislative history to glean the ‘basic intent of GINA’.⁷⁰ Quoting statements by legislators, it concluded that GINA’s goal was primarily ‘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”’.⁷¹ The court

⁶⁴ See *Id.* (noting that 6 of the 16 substantive GINA cases concerned the employer’s use or acquisition of medical information that did not constitute genetic information under GINA).

⁶⁵ 852 F. Supp. 2d 727 (W.D. Va. 2012).

⁶⁶ *Id.* at 729.

⁶⁷ *Id.*

⁶⁸ *Id.*

⁶⁹ *Id.* at 731.

⁷⁰ *Id.* at 730.

⁷¹ *Id.* (citing H.R. REP. No. 110–28, pt. 3, at 70 (2007); 2008 U.S.C.C.A.N. 112, 141) (emphasis added).

acknowledged that Congress included family history in its definition of ‘genetic information’ because it could be used ‘as a surrogate for genetic traits’, and could ‘be viewed to indicate that the individual himself is at an increased risk for that disease’.⁷² Nevertheless, it reasoned that information about a disease or disorder in family members is not ‘genetic information’ if ‘such information is *taken into account* only with respect to the family member with the condition and ‘not as genetic information with respect to any other individual’.⁷³ In other words, information about Poore’s wife’s diagnosis with multiple sclerosis had ‘no predictive value with respect to Poore’s genetic propensity to acquire the disease’,⁷⁴ and presumably was not ‘taken into account’ with respect to Poore’s health status. Therefore, according to the court, it did not constitute genetic information.

There is a certain logic to the *Poore* opinion. That GINA prohibits genetic discrimination based on presymptomatic genetic information as opposed to manifested genetic conditions could be read to suggest that it only prevents discrimination against people based on a *propensity* for genetic disease. Because a wife’s health condition certainly does not predict her husband’s genetic risks, it does not seem like genetic information understood in those terms.

Even so, the *Poore* court notes that GINA defines ‘genetic information’, in part, as ‘the manifestation of a disease or disorder in *family members* of an individual’.⁷⁵ Inexplicably, it does not grapple with this statutory language to consider whether a spouse is a ‘family member’. Nor does it examine GINA’s definition of ‘family member’ as ‘a dependent (as such term is used for purposes of section 1182(f)(2) of title 29 [the Employee Retirement Income Security Act of 1974 (“ERISA”)]) of such individual’.⁷⁶ Likewise, it does not discuss the interpretive guidance of the Equal Employment Opportunity Commission (‘EEOC’), which describes a ‘family member’ as a ‘person who is a dependent ... as the result of *marriage*, birth, adoption, or placement for adoption’.⁷⁷ In other words, *Poore* fails to consider who the relevant family members are or what constitutes a dependent under GINA.

There is a strong argument that ‘the definition for “dependent” includes relatives who are not blood-related (e.g., *spouse*, adopted child)’.⁷⁸ The EEOC took such a position in 2010 when promulgating the regulations to implement Title II, despite the fact that groups representing employers had submitted comments opposing the inclusion of such individuals. These groups argued that ‘dependents by adoption or placement for adoption should not be considered family members because genetic information about them would not indicate whether an individual protected by GINA might acquire a disease or disorder’.⁷⁹

⁷² *Id.* (citing H.R. REP. No. 110–28, pt. 1, at 36 (2007); 2008 U.S.C.C.A.N. 66, 80).

⁷³ *Id.* (citing H.R. REP. No. 110–28, pt. 2, at 27 (2007); 2008 U.S.C.C.A.N. 101, 105–106); *see also* Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,917 (Nov. 9, 2010).

⁷⁴ *Id.* at 731.

⁷⁵ 42 U.S.C. § 2000ff(4) (emphasis added).

⁷⁶ *Id.* § 2000ff(3).

⁷⁷ 29 C.F.R. 1635.3(a)(1) (emphasis added).

⁷⁸ AMANDA K. SARATA ET AL., CONG. RESEARCH SERV., R44311, EMPLOYER WELLNESS PROGRAMS AND GENETIC INFORMATION: FREQUENTLY ASKED QUESTIONS 1 & n.7 (2015) [hereinafter SARATA ET AL., WELLNESS]; but *see* ANDREWS ET AL., *supra* note 21, at 791 (arguing that the ‘definition of “family” member excludes spouses, but covers dependents, including those that result from marriage or adoption . . .’).

⁷⁹ 75 Fed. Reg. 68915 (citing Comments of Illinois Chamber of Commerce (ICC) and Chamber/SHRM).

The EEOC rejected this narrow interpretation of ‘dependent’ because GINA’s ‘explicit reference’ to ERISA, when defining family members as dependents, made it ‘absolutely clear’ that dependents, even if not biologically related, constitute family members under GINA.⁸⁰ Furthermore, health information about dependents through adoption or marriage could lead employers to discriminate against an employee based on her dependent’s medical condition to avoid ‘potential health care costs’ or ‘increased health insurance rates’,⁸¹ which the EEOC believed GINA intended to prohibit.⁸² The health information of spouses would surely pose an equally great risk of such employment discrimination as the health information of non-biological children (through adoption or marriage). Therefore, the EEOC concluded that spouses are dependents.⁸³

If this interpretation is correct, Poore’s wife’s multiple sclerosis is a manifestation of a disease in a family member, and therefore it constitutes genetic information under GINA.⁸⁴ Instead of engaging with these important semantic and definitional issues, however, the *Poore* court simply reached its conclusion based on two statements made during floor debates before GINA was passed. It offered no context for the legislators’ assertions that genetic information must be predictive of the employee’s health status and failed to assess how they relate to the statutory language Congress ultimately adopted.

Nevertheless, the *Poore* court set the groundwork for a two-tiered interpretative approach that other courts soon followed: ie 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 disorder is ‘taken into’ account in determining whether the employee has a propensity for disease. The following year, for example, *Allen v Verizon Wireless*⁸⁵ used similar reasoning to reject Queen Allen’s claim for discrimination under Title II of GINA. Allen alleged she had been denied short-term disability benefits based on her family history.⁸⁶ In requesting leave to care for her mother under the Family Medical Leave Act, she provided her employer, Verizon Wireless, with her mother’s ‘confidential medical information’,⁸⁷ which the court never described. She alleged that Verizon considered her mother’s medical information, which she asserted was genetic information under GINA, in denying her request for short-term disability benefits.⁸⁸

The court was skeptical that Allen’s employer used her mother’s medical information as ‘genetic ‘family history’. But even if her employer had, the court dismissed her claim on the grounds that Allen ‘failed to allege facts to raise a reasonable inference’ that

⁸⁰ *Id.* As others have pointed out, ERISA is a statute that addresses ‘employee benefits, including retirement and health benefits’, lending further support to this interpretation. SARATA ET AL., WELLNESS, *supra* note 78, at 1 n.7.

⁸¹ *Id.*

⁸² CONG. RESEARCH SERV., R44311, EMPLOYER WELLNESS PROGRAMS AND GENETIC INFORMATION: FREQUENTLY ASKED QUESTIONS 3 (2017), https://www.everycrsreport.com/files/20170404_R44311_283735bb7bf16657375105e8f573646ab92b9bf0.pdf (last visited Jun. 2, 2018).

⁸³ *Id.* at 3; 75 Fed. Reg. 68915 (Nov. 9, 2010) (citing S. Rep. No. 110–48 at 28, which indicates that ‘spouses and adopted children were included in the definition of family member for this exact reason’).

⁸⁴ 42 U.S.C. 2000ff (4)(A)(iii).

⁸⁵ No. 3:12-cv-482, 2013 WL 2467923 (D. Conn. June 6, 2013).

⁸⁶ *Id.* at *2

⁸⁷ *Id.*

⁸⁸ *Id.* at *23.

she was denied benefits ‘because of’ the alleged genetic information.⁸⁹ What is relevant for our purposes is the fact that the court quoted *Poore* with approval to describe the relevance of family medical history under GINA. As the court asserted,

evidence of a family member’s disease diagnosis is only considered ‘genetic information’ if used to *determine the likelihood of disease* in another individual. It is not considered ‘genetic information’ if it ‘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’.⁹⁰

Although this discussion was not central to the court’s ultimate resolution of the GINA claim, it reiterated the idea established in *Poore* that information about a family member’s diagnosis only sometimes constitutes genetic information. It went a step further than *Poore*, however, because this time the family member was a blood relative—a mother—as opposed to a non-biological relative, like the spouse in *Poore*. Although one can find some ambiguity as to whether a spouse is a family member under GINA,⁹¹ an employee’s mother unequivocally meets the definition of family member as an ‘individual who is a first-degree ... relative of such individual’.⁹² In spite of that unambiguous statutory language, *Allen* advocated, in *dictum*, *Poore*’s two-tier approach. In other words, a manifested genetic condition of a parent would not qualify for genetic information if it is not used ‘to determine’ the likelihood of disease or is not ‘taken into account’ with respect to the health status of the employee.

Applying a similar interpretive approach, *Conner-Goodgame v Wells Fargo Bank, N.A.*⁹³ decided a GINA retaliation claim in favor of the defendant. In that case, the plaintiff, Kaneshia Conner-Goodgame, claimed among other things that her employer discriminated against her in violation of GINA and discharged her in retaliation for having complained about discrimination under GINA.⁹⁴ She argued that she informed her supervisor at Wells Fargo Bank that her mother had been diagnosed with and died from AIDs, she claimed her supervisor disclosed that information to her co-workers, in violation of GINA.⁹⁵ The court disposed of her GINA claims on two grounds. First, it concluded that information about her mother’s AIDS diagnosis ‘does not constitute *genetic information* about a manifested disease or disorder’.⁹⁶ Citing to EEOC interpretations, it reasoned that GINA does not protect against discrimination on the ‘basis of impairments that have a genetic basis’ (ie manifested genetic conditions), but instead focuses on protecting against discrimination because an employer thinks its employee is ‘at increased risk of acquiring a genetic condition’.⁹⁷ Furthermore, it pointed out that HIV

⁸⁹ *Id.*

⁹⁰ *Id.* (quoting *Poore*, 852 F. Supp. 2d at 731) (emphasis added).

⁹¹ See *supra* text accompanying note 75–83.

⁹² § 201(3) (B).

⁹³ No. 2:12-cv-03426-IPJ, 2013 WL 5428448 (N.D. Ala. Sept. 26, 2013).

⁹⁴ *Id.* at *4.

⁹⁵ *Id.* at *2.

⁹⁶ *Id.* at *11.

⁹⁷ *Id.* (citing to and quoting Background Information for EEOC Final Rule on Title II of the Genetic Information Nondiscrimination Act of 2008, <http://www.eeoc.gov/laws/regulations/gina-background.cfm> (last visited Jun. 2, 2018)).

tests are not genetic tests and therefore the determination of her mother's AIDS status based on such tests 'could not be considered genetic information'.⁹⁸

This analysis misunderstands several aspects of GINA. That GINA does not protect against *impairments* with a genetic basis is true, but irrelevant. The plaintiff was not claiming that the genetic information at issue was the manifestation of a genetic condition in herself, which clearly would not be protected under GINA.⁹⁹ Instead, her claim was that information about the AIDS diagnosis of her mother was genetic information. While the court is correct that GINA protects against discrimination based on presymptomatic genetic risks, one of the ways it does that is by including information about 'the manifestation of a disease or disorder in family members'.¹⁰⁰ That her mother's diagnosis was based on HIV testing, which is not a genetic test, is also irrelevant. She was not suggesting that her mother's condition was diagnosed based on a genetic test. She merely claimed that she disclosed information about her mother's 'manifestation of a disease or disorder'.

Second, the *Conner-Goodgame* court rejected the plaintiff's assertion that her employer's 'disclosure of non-genetic information concerning [her] family member's disease or disorder' could be a basis for liability under GINA in this case. It found 'no support' for interpreting genetic information 'so strictly'.¹⁰¹ The court observed that the plaintiff 'had no chance of acquiring HIV in the future as a result of her deceased mother's AIDS', and therefore the family history provided no predictive information with regard to the employee. It also struggled with the notion that GINA protects non-genetic information concerning a family member, but not non-genetic information concerning a plaintiff herself. In essence, it feared the plaintiff's assertion that her mother's AIDS diagnosis was protected genetic information would 'give more protection' to the family member's information than to 'the actual employee's information'.¹⁰²

Again, as in *Poore*, there is a certain logic to the court's reasoning if one focuses on GINA's distinctions between presymptomatic genetic information and manifested genetic disease. Because infectious diseases are not generally heritable, it is unlikely that an employee's mother's AIDS diagnosis decades earlier poses a risk of future disease in the employee. Like the *Poore* court, however, the *Conner-Goodgame* court erred in ignoring GINA's plain language. In defining genetic information in part as 'the manifestation of a disease or disorder in family members', GINA did not distinguish between non-genetic and genetic disease in family members. The AIDS diagnosis in *Conner-Goodgame*'s mother, therefore, unambiguously fits within this definition of 'genetic information'.

The *Poore* two-tier approach to construing genetic information in terms of its predictive value continued in *Maxwell v Verde Valley Ambulance Co., Inc.*¹⁰³ In that case, plaintiff Matthew Maxwell alleged that his employer, Verde Valley Ambulance Co. ('VVAC'), required him, in violation of GINA, to 'disclose "genetic information" in his family medical history'. Maxwell had told his supervisor that he was disabled due to a leg injury sustained prior to his employment. As a result, his employer requested he

⁹⁸ *Id.*

⁹⁹ *Id.*

¹⁰⁰ 42 U.S.C. § 2000ff4(A).

¹⁰¹ 2013 WL 5428448 at *11.

¹⁰² *Id.*

¹⁰³ No. cv-13-08044-PCT-BSB, 2014 WL 4470512 (D. Ariz. Sept. 11, 2014).

receive a medical evaluation to determine whether he ‘was qualified’ to perform his employment duties.¹⁰⁴ When his supervisor requested a copy of the physician’s letter, she also received the health and occupational history form that Maxwell completed, which indicated that his grandfather had had cancer.¹⁰⁵ Maxwell alleged that VVAC violated GINA by ‘requesting, requiring, or purchasing genetic information’.¹⁰⁶

A key issue in addressing the claim was whether the plaintiff’s family medical history concerning his grandfather’s cancer was ‘genetic information’ under GINA. Quoting *Poore* and its reliance on legislative history, the *Maxwell* court emphasized that GINA’s purpose is to prevent discrimination based on 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’.¹⁰⁷ Like *Poore*, it concluded that a family member’s medical diagnosis does not constitute ‘genetic information’ under GINA if ‘such information is *taken into account* only with respect to’ the affected family member and ‘not as genetic information with respect to any other individual’.¹⁰⁸ Finding no evidence to suggest that Maxwell’s grandfather’s history of cancer ‘was “taken account” with respect to Plaintiff’, the court found a question of fact as to whether the information at issue was ‘genetic information’. Accordingly, it denied both parties’ motions for summary judgement.¹⁰⁹ Although the court left open the possibility that additional evidence could potentially support a conclusion that it was genetic information, it worried about the implication in the plaintiff’s argument that an employer could face ‘strict liability’ any time it ‘receives information about an employee’s family medical history’.¹¹⁰

The reasoning of the *Maxwell* court, in particular its unwillingness to conclude that the family history was ‘genetic information’ as a matter of law, is troubling in a few additional respects. First, as noted earlier, nothing in GINA suggests that the definition of genetic information depends on whether the manifested disease or disorder in an employee’s family member is *predictive* with respect to whether the employee is at risk for a genetic disease. The statute states unambiguously that a manifested disease in a family member constitutes genetic information.

Second, even if the definition of ‘genetic information’ required family medical history to be predictive of an employee’s future health risks, *Maxwell* is a case in which the family history was potentially predictive. Cancer has both genetic and environmental components. Its diagnosis in an employee’s relative therefore has potential predictive value in assessing future health risks in the employee. Whereas an employee’s wife’s diagnosis with multiple sclerosis and an employee’s mother’s AIDS diagnosis are not indicative of the employees’ future health risks, information about cancer in an employee’s second-degree relative has potential predictive value about his propensity for

¹⁰⁴ *Id.* at *13–14.

¹⁰⁵ *Id.* at *13.

¹⁰⁶ *Id.* at *14 (citing 42 U.S.C. § 2000ff-1(b)).

¹⁰⁷ *Id.* at *16 (quoting *Poore*, 852 F. Supp. at 730 (quoting H.R. REP. NO. 110–28, pt. 3, at 70 (2007), 2008 U.S.C.C.A.N. 112, 141)).

¹⁰⁸ *Id.* (quoting *Poore*, 852 F. Supp. at 730 (quoting H.R. REP. NO. 110–28, pt. 2, at 27 (2007), 2008 U.S.C.C.A.N. 101, 105)).

¹⁰⁹ *Id.* at *17. The court also denied the plaintiff’s motion for summary judgement on the grounds that he did not adequately address whether the employer’s acquisition of the alleged genetic information was inadvertent when it failed to direct the medical provider not to disclose Maxwell’s genetic information. *Id.* at *15.

¹¹⁰ *Id.* at *17.

cancer. It would seem, therefore, that such a family history should be genetic information as a matter of law: it both fulfills the definition and is consistent with the spirit of GINA.

Two recently decided cases also rely on the *Poore* methodology to assess whether family history constitutes genetic information. Although the information at issue in these cases does not constitute genetic information under even a broad construction, the cases' reliance on *Poore* is instructive. In *Carolina Rebecca Green v Whataburger*,¹¹¹ Ms. Green alleged a discrimination and retaliation claim under GINA based on information about her daughter's medical history, specifically the fact that her daughter needed surgery 'due to the possibility of cancer'.¹¹² The court correctly concluded that this information did not constitute 'the manifestation of a disease or disorder in family members' because her daughter had not yet been diagnosed with a condition.¹¹³ Nevertheless, the court's *dictum* suggested that to determine whether a family history is genetic information under GINA requires more than the fact that a family member has a manifested disease or disorder.

The court quoted the, by now, familiar language from *Poore* that the 'purpose of the family medical history provision' in defining genetic information is 'to prohibit employers from making a predictive assessment concerning an [employee's] propensity to get an inheritable genetic disease or disorder based on the occurrence of an inheritable disease or disorder in a [a] family member'.¹¹⁴ In so doing, it suggested that even if there was evidence of a manifested disease in the daughter, the court would have to determine whether such information was 'taken into account' only with respect to the daughter and 'not as genetic information with respect to any other individual'.¹¹⁵ Thus, it seemed to accept the two-tier analysis of *Poore*: (1) is there a manifested disease in a family member? and (2) is it taken into account to provide 'predictive value' with respect to the employee? The court was correct in concluding that the first-tier was not met (because Green's daughter had not been diagnosed with cancer). But the court erred in suggesting that a second analytic step would have been required, had a family history been established, to show that the family history was predictive in order to be considered 'genetic information'.

Finally, in *Gibson v Wayfair*,¹¹⁶ Toya Gibson brought a GINA claim alleging that Wayfair had terminated her employment based on information about her father's stroke and her mother's 'unspecified mental illness'.¹¹⁷ Again, in *dictum*, the court cited precisely the same language from *Poore* that *Whataburger* and the other cases described in this section used.¹¹⁸ It did not ultimately apply the two-tier analysis of *Poore*, however, because Gibson had not exhausted the administrative remedies with respect to the claims concerning her father's stroke¹¹⁹ and because there was 'no evidence that her mother was diagnosed with a specific mental disease or disorder'.¹²⁰ Thus, although

¹¹¹ No. 5:17-CV-243-DAE, 2018 WL 6252533 (W.D. Tex. Oct. 9, 2018).

¹¹² *Id.* at *3.

¹¹³ *Id.*

¹¹⁴ *Id.* at *2 (quoting *Poore v. Peterbilt of Bristol, LLC*, 852 F. Supp. 2d 727, 730 (W.D. Va. 2012)).

¹¹⁵ *Id.* (quoting *Poore*, 852 F. Supp. at 730 (quoting H.R. REP. NO. 110-28, pt. 2, at 27 (2007))).

¹¹⁶ No. 4:17-2059, 2018 WL 3140242 (S.D. Tex. June 27, 2018).

¹¹⁷ *Id.* at *4.

¹¹⁸ *Id.*

¹¹⁹ *Id.*

¹²⁰ *Id.* at *5.

the ultimate disposition was correct, the court's endorsement of *Poore's* narrow understanding as to when family history constitutes 'genetic information' under GINA is problematic.

II.B. Broad Construction of 'Genetic Information'

While *Poore* and its progeny construe 'genetic information' narrowly, in terms of whether it was 'taken into account' for its predictive value, another line of cases interprets the definition quite differently. They simply examine whether the information in question falls within the definitional language of GINA. For example, in *Jackson v Regal Beloit America*,¹²¹ the court easily concluded that under 'the plain language of GINA', Regal Beloit America ('Regal') had unlawfully requested genetic information from Shelia Jackson when the physician who performed an employment-related medical examination requested medical records that 'contained protected "genetic information" in the form of her family history'.¹²² Unlike *Poore* and its progeny, the court did not suggest that another level of inquiry was required to assess whether the family history was 'taken into account' with respect to the employee's propensity for disease. Not only did the court find a GINA violation for an 'unlawful request' for genetic information,¹²³ it also found that the plaintiff had established a retaliation claim under GINA. Jackson demonstrated that Regal's displacement and termination of her immediately followed her refusal to turn over requested medical records containing 'protected genetic information', and Regal offered no 'legitimate rationale' for its adverse employment decisions.¹²⁴

Similarly, in *Thomas Montgomery et al. v Union Pacific Railroad*,¹²⁵ the employer requested medical records 'without a warning not to disclose genetic information'.¹²⁶ Although the court considered the plaintiff's GINA claim to be 'very weak', it was unwilling to grant the employer summary judgement with respect to the plaintiff's claim that his employer had unlawfully requested genetic information by requesting medical records 'without instructions to redact family history'.¹²⁷ The implication, again, was that family history alone, without consideration of whether the employer 'took it into account' with respect to the employee's propensity for disease, constituted genetic information.

In other cases that also construe genetic information broadly, the facts might have yielded the same results even under the narrower interpretive approach of *Poore et al.* These cases are nevertheless instructive because they avoid *Poore's* two-tier analysis and focus only on GINA's simple definition. For example, in *Punt v Kelly Services*,¹²⁸ employee Kristin Punt alleged that she was terminated from her employment

¹²¹ No. 16-134-DLB-CLS, 2018 WL 3078760 (E.D. Ky. June 21, 2018).

¹²² *Id.* at *15–16. Although the doctor was working as an agent for the employer, the court rejected the employer's attempts to argue the acquisition of the information was inadvertent because the employer had failed to use the EEOC regulations' 'safe-harbor language or similar language' to direct the health care provider not to provide it with genetic information. *Id.* at *16–17. Moreover, it reasoned that the request for medical information was 'extremely broad' and therefore made it likely that the employer would obtain genetic information. *Id.* at *17.

¹²³ *Id.*

¹²⁴ *Id.* at *18.

¹²⁵ No. CV-17-00201-TUC-RM, 2018 WL 6110930 (D. Ariz. Nov. 21, 2018).

¹²⁶ *Id.* at *8.

¹²⁷ *Id.* at *9.

¹²⁸ No. 14-cv-02560-CMA-MJW, 2016 WL 67654 (D. Colo. June 6, 2016).

based on her family history of cancer in violation of GINA. She had shared information with co-workers that her ‘mother, grandmother, great-grandmother, cousin, and aunt were all diagnosed with breast cancer’.¹²⁹ The court readily concluded that such information ‘is the type of genetic information implicated by GINA’, not specifically because it suggested predictive potential, but because it met the statutory definition of ‘the manifestation of a disease or disorder in family members’.¹³⁰

In spite of this more expansive understanding of GINA, however, Punt did not succeed because she failed to allege ‘sufficient evidence’ that her termination was based on her genetic information.¹³¹ While she faced the same challenge in establishing discriminatory intent that many plaintiffs face in bringing employment discrimination claims,¹³² she was not thwarted by a court’s unwillingness to apply the plain language of GINA in establishing that the information at issue was genetic information.

*Lee v City of Moraine Fire Dept.*¹³³ similarly concluded that an employee’s family history constitutes genetic information. In that case, David Lee’s employer, Moraine Fire Department updated its requirements for health and wellness physicals. As part of the revised process, Lee completed a questionnaire, which asked about family history of heart disease.¹³⁴ Lee brought claims under GINA alleging that his employer had ‘unlawfully requested [his] genetic information and family history’.¹³⁵ The court easily granted his motion for summary judgement on this basis. It found that information about a family history of heart disease meets one of the statutory definitions of ‘genetic information’.¹³⁶ In addition, it concluded that the question on the health form—‘Is there a family history of heart disease in your parents and siblings?’—violated GINA’s prohibition of requests for genetic information.¹³⁷ Like the *Punt* court, the *Lee* court could have interpreted the information at issue to be genetic information under the more narrow, *Poore* analytic approach. But more importantly it merely examined whether the information met the statutory definition. It did not examine whether the information about family history was ‘taken into account’ with respect to the propensity of disease in the plaintiff.

¹²⁹ *Id.*

¹³⁰ *Id.* at *13 (quoting 42 U.S.C. § 2000ff(4)(A)).

¹³¹ *Id.*

¹³² *Id.*

¹³³ No. 3:13-cv-222, 2015 WL 914440 (S.D. Ohio Mar. 3, 2015).

¹³⁴ *Id.* at *1–2.

¹³⁵ *Id.* at *11. He also brought a claim under the Age Discrimination in Employment Act, 29 U.S.C. §§ 623(a)(1), because of the different physical requirements for individuals like him over the age of 40 and those under the age of 40. *Id.* at *5.

¹³⁶ *Id.* at *11 (quoting 42 U.S.C. § 2000ff(4)(A)(iii) (stating that genetic information is, in part, ‘information about . . . the manifestation of a disease or disorder in family members of the individual’)).

¹³⁷ Furthermore, unlike the *Maxwell* court, it noted that the employer’s acquisition of the genetic information was not inadvertent and it was not absolved of liability merely because a health care provider and not the employer created the questionnaire. The court quoted the implementing regulations, which note that an employer is responsible for telling ‘health care providers not to collect genetic information, including family medical history, as part of a medical examination intended to demonstrate the ability to perform a job, and must take additional reasonable measures within its control if it learns that genetic information is being requested or required’. *Id.* at *12 (quoting 29 C.F.R. § 1635.8(d)).

Similarly, the court in *EEOC v Grisham Farm Products, Inc.*¹³⁸ had little difficulty concluding that information about the health of family members constitutes genetic information. In that case, the requests for information about family history were more indirect. Defendant Grisham Farm Products, Inc. required job applicants to fill out a ‘three-page “Health History”’ form. One of the questions asked whether applicant Phillip Sullivan had ‘‘consulted’’ a healthcare provider ‘‘within the past 24 months’’¹³⁹ and whether ‘future ... diagnostic testing ... [has] been recommended or discussed’.¹⁴⁰ Although the questionnaire did not directly ask about the health of family members, the court reasoned that Sullivan’s responses would reveal ‘family history or risk factors’¹⁴¹ if Sullivan indicated that, despite having no manifestations of a medical condition, he had consulted with a physician, or a health care provider had recommended diagnostic testing. In other words, even indirect queries about health status that could lead to medical information about family members (or risk factors) constitute a violation of GINA’s prohibition of requests for genetic information.¹⁴² As a result, the court awarded damages to Sullivan.¹⁴³

Lowe v Atlas Logistics Group Retail Services (Atlanta), L.L.C.,¹⁴⁴ the last in the line of cases broadly construing genetic information, is quite different, factually speaking, from the other cases. It is also the most notorious, described in the press as the ‘devious defecator’ case.¹⁴⁵ The case originated with a ‘mystery employee’ who ‘habitually’ defecated in one of the warehouses of Atlas Logistics Group Retail Services (‘Atlas’).¹⁴⁶ In an attempt to identify the offender, Atlas requested that some of its employees, including plaintiffs Jack Lowe and Dennis Reynolds, submit to a cheek swab for forensic DNA analysis to compare their DNA with that of the ‘offending fecal matter’. Neither was found to be a match.¹⁴⁷ Both, however, filed charges of discrimination with the EEOC alleging that their employer had violated GINA in requesting and requiring them to provide, and in disclosing, their genetic information.¹⁴⁸ While the EEOC dismissed the charges, the federal district court found that Atlas had violated GINA.

The case turned on whether ‘genetic information’ applied to the results of the forensic DNA analysis of Lowe and Reynolds. This method of identification determines genetic variants in non-coding regions of the DNA, but does not determine propensity

¹³⁸ 191 F. Supp. 3d 994 (W.D. Mo. 2016).

¹³⁹ *Id.* at 995.

¹⁴⁰ *Id.* at 998.

¹⁴¹ *Id.*

¹⁴² *Id.* at 997 (quoting 29 C.F.R. § 1635.8(a) (noting that GINA prohibits employers from ‘making requests for information about an individual’s current health status in a way that is likely to result in a covered entity obtaining genetic information’).

¹⁴³ *Id.* at 998 (also awarding damages for violations of the American with Disabilities Act).

¹⁴⁴ 102 F. Supp. 3d 1360 (N.D. Ga. 2015).

¹⁴⁵ See eg Gina Kolata, ‘Devious Defecator’ Case Tests Genetic Law, *N. Y. TIMES*, May 29, 2015, <https://www.nytimes.com/2015/06/02/health/devious-defecator-case-tests-genetics-law.html> (last visited May 15, 2018). This case is also believed to be the first GINA case to go to trial. Natasha Gilbert, *Why the ‘Devious Defecator’ Case is a Landmark for US Genetic-Privacy Law*, *NATURE*, June 25, 2015, <https://www.nature.com/news/why-the-devious-defecator-case-is-a-landmark-for-us-genetic-privacy-law-1.17857> (last visited May 15, 2018).

¹⁴⁶ 102 F. Supp. 3d at 1361.

¹⁴⁷ *Id.*

¹⁴⁸ *Id.* at 1363.

for disease.¹⁴⁹ Focusing initially on the text of the statute, the court concluded that ‘the unambiguous language of GINA covered Atlas’ requests for Lowe’s and Reynolds’ genetic information’.¹⁵⁰ The definition of genetic information includes, in part, information about an ‘individual’s genetic tests’,¹⁵¹ which are defined as analyses of ‘human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations or chromosomal changes’.¹⁵² Since the forensic analysis of the employee’s DNA detected ‘genotypes and mutations’, it met the definition of a genetic test and therefore the results were genetic information under GINA.¹⁵³

Atlas argued, however, that the spirit and legislative history of GINA required the definition of genetic tests to be limited to those ‘related to one’s propensity for disease’.¹⁵⁴ It pointed to GINA’s goal of preventing the misuse of genetic information and, like *Poore et al.*, quoted legislators expressing the view that the ‘intent of GINA was to be limited to combating discrimination based on one’s propensity for disease’.¹⁵⁵ It also quoted the same language upon which the *Poore* court relied: that GINA prohibits discrimination based on 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’.¹⁵⁶

The *Lowe* court was not persuaded by Atlas’ defense. First, it reasoned that Atlas’ understanding of genetic testing and information would ‘render[] other language in GINA superfluous’.¹⁵⁷ For example, Congress explicitly excluded from the definition of ‘genetic test’ certain types of genetic analysis that do not establish disease propensity, such as ‘DNA analysis ... for purposes of human remains identification’ and ‘analysis of DNA identification markers for quality control to detect sample contamination’.¹⁵⁸ Such language, the court reasoned, would be ‘unnecessary’, if Atlas were right that any DNA analysis that did not identify disease propensity fell outside the purview of GINA.¹⁵⁹

Second, it noted that legislative statements demonstrating instances in which GINA could protect people identified to be at an increased risk of diseases were not ‘exhaustive’ examples.¹⁶⁰ More important, the court noted, the statements (that *Poore et al.* rely upon) suggesting that GINA was *limited* to information demonstrating disease propensity expressed the views of only ‘a handful of legislators’ and did not reflect the view of Congress.¹⁶¹ Instead, these statements were attempts to persuade fellow legislators that GINA’s definition of ‘genetic information’ was too broad and should be narrowed.¹⁶²

¹⁴⁹ *Id.* at 1362.

¹⁵⁰ *Id.* at 1365.

¹⁵¹ 42 U.S.C. § 2000ff(4)(i).

¹⁵² 42 U.S.C. § 2000ff(7).

¹⁵³ 102 F. Supp. 3d. at 1365.

¹⁵⁴ *Id.* at 1365–66.

¹⁵⁵ *Id.* at 1368; *Id.* at 1367–68 (describing the late Representative Louise Slaughter’s discussions of examples of how GINA would protect individuals when genetic tests revealed they were at increased risk of certain diseases).

¹⁵⁶ *Id.* at 1368 (citing H.R. REP. No. 110–28, pt. 3, at 70 (Mar. 29, 2007)) (emphasis added).

¹⁵⁷ *Id.* at 1366.

¹⁵⁸ *Id.*

¹⁵⁹ *Id.* (citing 42 U.S.C. § 2000ff-1(b)(6)).

¹⁶⁰ *Id.* at 1368.

¹⁶¹ *Id.*

¹⁶² *Id.*

As the *Lowe* court observed, their efforts failed and as did other efforts to narrow the definition.¹⁶³

The court also noted that the EEOC regulations use the same language as GINA. Moreover, not all of its examples of genetic information include information that indicates a propensity for disease. The regulations state, for example, that information from ‘DNA testing to detect genetic markers associated with information about ancestry’ or ‘DNA testing that reveals family relationships such as paternity’ constitutes ‘genetic information’. Furthermore, the kinds of genetic tests that are not protected under GINA, according to the regulations, do not include the genetic forensic analysis used by Atlas.¹⁶⁴ For all of these reasons, the court followed the ‘plain meaning of the statute’s text’ and determined that Atlas had violated GINA in requesting DNA forensic analysis of its employees.¹⁶⁵

III. TOWARD A CONSISTENT UNDERSTANDING OF ‘GENETIC INFORMATION’

As Part II has shown, the courts have followed two very different approaches in interpreting genetic information. The *Poore* approach tries to narrow the definition so that ‘genetic information’ is understood only in terms of its predictive value. In contrast, courts like *Lowe* and *Punt* follow the plain language of the statute to construe genetic information broadly, even in instances where the information may not necessarily indicate a propensity for disease.

III.A. Why Courts Should Adopt the Broad Construction of ‘Genetic Information’

As the *Lowe* court notes, the presumption should be to follow the plain meaning of the statute.¹⁶⁶ Where statutory language is unambiguous, the words chosen by the legislature are ‘the most reliable source of legislative intent’¹⁶⁷ and there is no reason to probe further to construe the meaning of the terms.¹⁶⁸ In other words, courts should generally ‘look to other interpretive tools, including the legislative history’ only when there is ambiguity in the text.¹⁶⁹ For the most part, GINA’s language defining genetic information and genetic test is ‘plain and admits of no more than one meaning’.¹⁷⁰ Under this interpretive approach therefore, the text alone should be sufficient to construe the meaning of ‘genetic information’.

Even in *Poore*, where there was potential ambiguity as to whether the term ‘family member’ applies to spouses, the court never considered whether this aspect of the definition was ambiguous generally or as applied to that case. Similarly, the other courts

¹⁶³ For example, the FBI suggested a narrower definition of a genetic test: ‘analysis of human DNA, RNA, chromosomes, proteins, or certain metabolites in order to detect *disease-related* genotypes or related phenotypes.’ *Id.* (quoting H.R. REP. 110–28, pt 3, at 68).

¹⁶⁴ *Id.* at 1370 (quoting 29 C.F.R. § 1635.3(f)(1)-(2)).

¹⁶⁵ *Id.* at 1369.

¹⁶⁶ *Cnty. for Creative Non-Violence v. Reid*, 490 U.S. 730, 739 (1989) (‘The starting point for our interpretation of a statute is always its language.’).

¹⁶⁷ NORMA SINGER & SHAMBI SINGER, 2A SUTHERLAND STATUTORY CONSTRUCTION § 45:5 (7th ed., 2017).

¹⁶⁸ *Caminetti v. United States*, 242 U.S. 470, 485 (1917) (noting that in those instances the ‘duty of interpretation does not arise and the rules which are to aid doubtful meanings need no discussion’).

¹⁶⁹ See *Matter of Tranwest Resort Properties, Inc.*, 881 F.3d 724 (9th Cir. 2018) (quoting *Exxon Mobil Corp. v. Allapattah Servs., Inc.*, 545 U.S. 546, 567 (2005)).

¹⁷⁰ *Caminetti*, 242 U.S. at 485.

that relied on legislative intent to narrow their understanding of genetic information never discussed whether the statutory language was ambiguous. Nor did they offer any other rationale to justify an interpretation that goes against the plain meaning of GINA's definition of genetic information. Although these cases did not discuss their methodology, their approach hints at a view that the 'meaning—or ambiguity—of certain words or phrases may only become evident when placed in context'.¹⁷¹ As the Supreme Court noted in *King v Burwell*, 'when deciding whether the [statutory] language is plain', courts 'must read the words "in their context and with a view to their place in the overall statutory scheme"'.¹⁷² When one considers both that Congress intended to draft a broad definition and that it is impossible to draw tidy lines between genetic and non-genetic information, the definition read in context argues in favor of the broad construction.

Even if an examination of legislative intent were necessary to determine the full meaning of 'genetic information' in these GINA cases, the legislative history and purpose of GINA support the broader construction. As the *Lowe* court noted, the fact that legislators cited examples of genetic information indicating a propensity for disease does not mean that 'genetic information' includes only such information. Moreover, there is scant support in the legislative history for the view that family history is genetic information only if it is predictive of an employee's future health. After all, such a view comes from the testimony of 'only a handful of legislators who lost the battle over the breadth of the definition of 'genetic information'.¹⁷³

Further, the broad goal of GINA was 'to fully protect the public from and allay concerns about discrimination'.¹⁷⁴ As part of that effort, Congress expressly chose a definition of genetic information that is among the broadest of those used in genetics legislation. Not only did it use family history, which many state legislatures explicitly excluded from the definition, it included family members who were not genetically related. In addition, it did not define family history in terms of 'inheritable' manifested diseases of disorders in family members. While Congress could easily have narrowed its definition to include only family history that is expressly predictive of future health risks, it did not do so, in spite of some legislators' concerns about adopting too broad a definition. It seems clear from the ultimate definition that Congress adopted, even in the face of these criticisms, that its goal was to protect genetic information expansively.

The EEOC's drafting of the final rule and response to comments offers some insights as to why Congress may have defined 'genetic information' broadly and failed to limit the definition to information about predictive risks. Although concerns about discrimination based on future health risks were the impetus for GINA, the EEOC did not modify its definition of family history in the ways suggested by *Poore* and progeny. Indeed, in drafting the Final Rule, it rejected requests from some employer groups to narrow the regulation's definition of 'family medical history' to include only modified

¹⁷¹ *Brown v. Williamson*, 529 U.S. 120, 132 (2000).

¹⁷² 135 S. Ct. 2480, 2489 (2015) (quoting *Id.* at 133). The court's duty 'after all is "to construe statutes, not isolated provisions."' *Id.* (quoting *Graham County Soil and Water Conservation Dist. v. United States ex rel. Wilson*, 559 U.S. 280, 290 (2010)); see also *Robinson v. Shell Oil Co.*, 519 U.S. 337, 341 (1997) (Courts must consider 'the language itself, the specific context in which that language is used, and the broader context of the statute as a whole').

¹⁷³ 102 F. Supp. 3d. at 1368.

¹⁷⁴ 42 U.S.C. § 2000ff.

diseases or disorders in family members that were ‘inheritable’ for a few reasons.¹⁷⁵ First, the EEOC wanted the language of the regulation to be ‘consistent with the plain language of the statute, which also does not include the word “inheritable”’. In addition, given how rapidly the field of genetics is developing, the EEOC was concerned about the ‘significant compliance and enforcement problems’ for covered entities or EEOC investigators in determining whether a disease or disorder in family members is “‘inheritable’ or has a genetic basis’.¹⁷⁶

The facts in *Maxwell*, involving a grandparent with cancer, illustrate this difficulty, given that cancer can but does not always have a strong genetic component.¹⁷⁷ How would a covered entity or EEOC investigator determine whether this particular instance of cancer is inheritable or has a genetic basis? It is likely that Congress recognized such concerns and opted for a bright-line rule that would cover all predispositions to genetic disease, even if, in some instances it might be overly broad. Attempting to modify family history as ‘inheritable’ manifested disease or disorder in family members would have presented interpretation problems. It would also have risked the possibility of too narrow an understanding of genetic information and the possibility that some information that might be predictive of future health risk would be incorrectly deemed not to constitute relevant family history. Given the impossibility of a definition that maps perfectly onto propensity for health risk, Congress seemed quite clearly to prefer a definition that was overly broad to one that was overly narrow. Thus, the statutory language, GINA’s goal to ensure broad protection, and the implementing regulations all suggest that the understanding of family history as defined under GINA should not be restricted in the way that *Poore*, *Allen*, *Connor-Goodgame*, *Maxwell*, *Carolina Rebecca Green*, and *Gibson* suggest.

Not only is the *Poore* interpretation inconsistent with the goals of Congress and GINA’s unambiguous statutory language, it also presents another and more subtle difficulty in its understanding of the meaning of family history. Even if one were to accept the view that genetic information is (or should be) limited to information predictive of future health risks in an employee, *Poore*’s two-tier test to determine whether family history is genetic information requires a showing that a manifested disease or disorder in a family member is ‘taken into account’ not only with respect to the family member and but also with respect to the health risks of the employee.¹⁷⁸ This language suggests not only that the health status of the family members must reveal a propensity of disease in the employee but also that it must be *understood* as such, ie ‘taken into account’ with respect to the employee.

The *Poore* lineage does not explicitly describe who must take it into account, but the reasoning of these cases suggests it must be the covered entity. The *Poore* court explains, for example, that GINA used family history to define ‘genetic information’ because *employers* could ‘potentially use [it] “as a surrogate for genetic traits”’. It makes this statement right before it discusses the need for the family history to be ‘taken

¹⁷⁵ 75 Fed. Reg. 68912-01 (Nov. 9, 2010).

¹⁷⁶ In addition, the EEOC was not persuaded by the concerns of these groups that charges would be filed under GINA based on a common cold or the flu in family members. *Id.*

¹⁷⁷ Suter, *supra* note 13, at 703.

¹⁷⁸ 852 F. Supp. 2d at 730 (citing H.R. REP. No. 110–28, pt. 2, at 27 (2007); 2008 U.S.C.C.A.N. 101, 105–106; see also Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68,917 (Nov. 9, 2010).

into account' with respect to the employee, implying it is the employer who must perceive the information in that light.¹⁷⁹ The passive voice hides the actor, but who else could the court have imagined would interpret the information other than the employer? Under this view, therefore, the test of the predictive value of the health status of family members does not depend on whether the information objectively demonstrates a propensity for disease in the employee, but on whether the covered entity *perceives* this family medical history as genetic or heritable; whether it 'takes into account' the relative's health status in predicting a future health risk for the employee.

Under the facts of *Poore* and *Conner-Goodgame*, there may not be much distinction between an objective assessment of and the employer's view about the predictive value of a family member's health status. One could argue coherently under the facts of *Poore* and *Conner-Goodgame* that the family history—an employee's spouse's diagnosis with multiple sclerosis and an employee's mother's diagnosis with AIDs—reveals nothing about the propensity of disease in the employees under any objective assessment. Similarly, in both cases the employers did not (and one would not expect them to) interpret the family history as suggesting a propensity for disease.

In the *Maxwell* case, however, it is hard to make such an argument. One cannot claim definitively that cancer in a second-degree relative has no predictive value, objectively speaking. A family history of cancer might well have some such value, although without more information it is unclear how predictive it is. Even so, the *employer* might not 'take into account' the employee's grandfather's cancer with respect to the employee's health, even if it should have.¹⁸⁰ Or the employer might assert that it has not done so, even if it has, a point that would be hard to disprove.

To make the distinction more concrete, imagine that an employee's relative had cancer, but an employer claims that it did not 'take into account' that information with respect to the employee's future health. If, in fact the relative's cancer had a genetic basis and therefore it was inheritable, this would be genetic information under an objective assessment because the family history would reveal a propensity for disease in an employee. But if the definition depends on the employer's perception of the relevance of this information to the employee's health, it would not be genetic information. Similarly, if the employer wrongfully claimed it had not taken the information into account and the employee could not prove otherwise, it also would not be genetic information under this test. Defining genetic information in terms of *the employer's* understanding and interpretation of the information essentially narrows the definition too much. Even if the family history is predictive, it will not be genetic information if the *employer* does not (or persuasively claims not to) perceive it as such.

Defining genetic information in this manner therefore depends on the employer's state of mind, which is problematic for a few reasons. First, absolutely nothing in GINA or the EEOC regulations suggests that Congress intended genetic information to depend on the employer's understanding of the information. Worse, it substantially weakens one of the benefits of the privacy protections of GINA, which, as Jessica Roberts

¹⁷⁹ *Id.* (citing H.R. REP. NO. 110-28, pt. 1, at 36 (2007), 2008 U.S.C.C.A.N. 66, 80).

¹⁸⁰ 2014 WL 4470512 at *17.

has noted, bolster the anti-discrimination prohibitions.¹⁸¹ GINA is ‘not a typical antidiscrimination statute’. Unlike the vast majority of federal antidiscrimination laws, which prohibit discriminatory actions, but do not prohibit covered entities from ‘seeking—or even disclosing—information related to other kinds of protected statuses’, GINA restricts employers from acquiring (‘requesting, requiring, or purchasing’) genetic information.¹⁸² As she notes, this privacy provision helps combat discrimination by making ‘intent ... irrelevant’.¹⁸³ Whereas employment discrimination claims generally require the challenging task of proving an employer’s discriminatory intent—ie that the employment decision was based on the protected status¹⁸⁴—GINA provides an avenue for relief under the ‘privacy’ provision that should not depend on establishing the employer’s state of mind.¹⁸⁵

The *Poore* lineage of cases limits this protection by requiring the employee to show not only that there is a family history, but also that the employer construes the family history as genetic information by ‘taking it into account’ with respect to the employee’s health risks.¹⁸⁶ If this understanding of genetic information is correct, it requires plaintiffs to establish their employers’ mindsets not only with respect to whether employment decisions were based on protected information, but also whether the information at issue is even protected under GINA.

Had Congress wanted to define ‘genetic information’ in terms of the employer’s perceptions it easily could have. After all, it defined disability under the ADA, in part, in terms of perceptions. Specifically, in drafting that antidiscrimination legislation, Congress adopted a definition of disability that includes objective information—whether one has had an ‘impairment that substantially limits one or more major life activities’—as well as information related to perceptions—whether one has a ‘record of such an impairment’, or whether one is ‘regarded as having such an impairment’.¹⁸⁷ GINA, in contrast, does not define ‘genetic information’ in terms of the employer’s or anyone else’s perceptions. None of the various definitions of genetic information discuss or refer to how the information is understood or ‘taken into account’ by the employer or anyone else.

¹⁸¹ See Jessica Roberts, *Protecting Privacy to Prevent Discrimination*, 56 WM. & MARY L. REV. 2097, 2128 (2015) (describing GINA as having providing ‘both privacy and antidiscrimination protections’, where the former works, in part to prevent discrimination by prohibiting ‘attempts to obtain genetic information’) [hereinafter, Roberts, *Protecting Privacy*].

¹⁸² *Id.* at 2130.

¹⁸³ *Id.* at 2149 (noting also that the privacy protection is ‘preemptive’ in that it allows the employee to challenge an employer’s ‘prying’ before any discriminatory actions occur).

¹⁸⁴ *Id.* at 1249–50.

¹⁸⁵ *Id.* at 1254 (describing the first GINA case settled by the EEOC, which did not require the employee to ‘establish why she denied employment or whether the denial was appropriate just that the employer made an inquiry related to her genetic information by asking for her family history’). Similarly, when the EEOC promulgated the final rule, it removed earlier references to ‘deliberate acquisition’ with respect to the prohibitions of acquisition of genetic information, indicating that the privacy violations of GINA did not require ‘specific intent’. As Professor Ajunwa notes, the EEOC ‘recognized the difficulty for a claimant to prove deliberate acquisition of genetic information by the accused’, eliminating a hurdle that might be insurmountable in the way that proving intent to discriminate can be insurmountable. Ajunwa, *supra* note 12, at 102 (describing Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68, 912 (U.S. Equal Emp’t Opportunity Comm’n Nov. 9, 2010) (to be codified at 29 C.F.R. pt. 1635)).

¹⁸⁶ *Id.* at 1250.

¹⁸⁷ 42 U.S.C. § 12101 (1).

III.B. The Impossibility of Defining ‘Genetic Information’ Precisely

What the two judicial approaches to interpreting GINA reveal is not just different methodologies of statutory interpretation. They also underscore the impossible task of defining genetic information so that it protects precisely the kind of information legislators had in mind when drafting genetic antidiscrimination laws. These struggles arise because of the ‘scientifically dubious dichotomy between genetic and non-genetic information’.¹⁸⁸ Any definition attempting to distinguish the two will inevitably suffer from over- and/or underinclusiveness because the line between genetic and non-genetic medical information is incredibly blurry. Medical information lies on a spectrum with respect to the degree that genes and environment play a role in the development of disease. Even illnesses that lie on either end of the spectrum, such as phenylketonuria (‘PKU’), an inherited condition, and AIDS, a disease caused by infection with HIV, are not purely genetically or environmentally based. Although PKU is a classic genetic disease, environmental factors such as the presence or absence of the amino acid phenylalanine in one’s diet can determine whether the symptoms of PKU develop. Conversely, some genetic factors can influence whether HIV infection will lead to AIDS.¹⁸⁹

While genetic antidiscrimination laws aim to protect against discrimination based on presymptomatic genetic information, efforts to draft such legislation present difficult choices about how to define ‘genetic information’. Should the definition be narrow so it does not protect against uses of ‘non-genetic information’ or should it be broader so it does not leave out information that reveals a propensity for future illness. Defining ‘genetic information’ as the result of a genetic test—analysis of RNA and DNA, for example—is one way of avoiding overinclusiveness because it would not include information about a spouse’s medical condition or a parent’s infectious disease. But even this definition can be overbroad by including information that does not address propensity for disease, as happened in *Lowe*.

Moreover, that approach is generally underinclusive; after all, before GINA was enacted, employers were far more likely to ask questions about an employee’s family history than subject employees to forensic DNA analysis. Defining ‘genetic information’ in terms of genetic test results would not include information about genetic disease in an employee’s family member, even if it demonstrated a higher risk of genetic disease in the employee. If an employee’s father has Huntington’s disease, the employee faces a 50% risk of developing Huntington’s.¹⁹⁰ And if her mother has heritable breast cancer, her risk of inheriting the gene is 50%, which would subject her to a life-time increased risk of breast or ovarian cancer.¹⁹¹ Congress, therefore, opted for a broader definition that included family history, whether or not it was based on ‘inheritable’ disease.

The problem, as *Poore* and *Conner-Goodgame* demonstrate, however, is that Congress’ definition is sometimes overly inclusive. Not all family history—such as a wife’s illness or a mother’s infectious disease—is indicative of a genetic risk. If Congress

¹⁸⁸ Rothstein, *GINA*, *supra* note 2, at 839.

¹⁸⁹ See Lucia Lopalco, *CCRS: From Natural Resistance to a New Anti-HIV Strategy*, 2 *VIRUSES* 574, 574 (2010).

¹⁹⁰ Richard Myers, *Huntington’s Disease Genetics*, 1 *NEURORX* 255 (2004).

¹⁹¹ The two main mutations associated with heritable breast cancer, BRCA1 and BRCA2, present a 65–80% life-time risk of breast cancer and a 20–45% risk of ovarian cancer in female carriers. Jessica Chan et al., *Reproductive Decision-Making in Women with BRCA1/2 Mutations*, 26 *J. GENET. COUNSELING* 594, 594 (2017).

had narrowed the definition to include only family history where the manifested disease in relatives is inheritable or has a genetic basis, that definition would be problematic in different ways. While it might be more precise and consistent with GINA's goal of protecting against presymptomatic genetic discrimination, it requires lines to be drawn between diseases in family members that are inheritable and not heritable. In other words, it simply moves the line-drawing problem between genetic and non-genetic information from the employee's health status to that of the employee's relatives. How is such a line to be drawn if we do not fully understand the extent of the role of genetics with respect to the majority of diseases? And, even if science could discern the extent of heritability for all diseases, how heritable must something be to fit within the definition?

Furthermore, this approach essentially leaves the line drawing to employers and ultimately EEOC investigators to determine whether employers have violated GINA. If the test is objective heritability of disease in relatives, employers hardly have the expertise to discern whether the medical condition is genetic or not. EEOC investigators may not be much better equipped. If we go a step further and follow the *Poore* approach, which requires evidence that the employer *viewed* the manifested disease in the family member as inheritable before it can be considered 'genetic information', that is highly problematic for employees. Employers have too many incentives to 'perceive' health status in a family member as irrelevant to the future health of the employee so they can limit their liability under GINA. What stops the employer from alleging it did not consider family history in assessing an employee's health risks, even if it actually did? And how would an employee be able to establish the true mindset of the employer with respect to this information to determine whether the employer (correctly or incorrectly) viewed it as predictive with respect to the future health of the employee?

These problems therefore argue for treating family history as genetic information, whether or not it can be demonstrated that a relative's manifested condition is inheritable. Although such a bright-line rule is overinclusive in certain instances, it avoids the impossible task of distinguishing between genetic and non-genetic disease in family members and it fully protects against discrimination based on presymptomatic genetic risks.

III.C. The Problem of Genetic-Specific Legislation

Given the inevitable over- and underinclusiveness of any definition of 'genetic information', no definition will make everyone happy. But that is the price of any genetics-specific legislation and the problematic conceptual exercise of trying to distinguish genetic information from other medical information. These semantic and definitional challenges, however, also raise substantive issues about the propriety of attempting to grant genetic information special treatment and protection in the first place.¹⁹²

Perhaps there is something about presymptomatic genetic information that is truly different from other medical information, although as I describe in great detail in earlier work, I am skeptical. Certainly there are aspects of some (but not all) genetic infor-

¹⁹² See eg Suter, *supra* note 13; Mark A. Rothstein, *Genetics Exceptionalism and Legislative Pragmatism*, 35 HASTINGS CTR. REP. 27 (2005). Genetics exceptionalism can apply to policy approaches that provide special protections just for genetic information. There is another sense of genetics exceptionalism, or perhaps better described as genetics essentialism that I am not discussing here. This notion views genes as uniquely important in explaining illness and who we are. See eg Ajunwa, *supra* note 12, at 85–87.

mation that warrant its protection—its predictive capacity, its hidden nature, its being out of our control, etc.¹⁹³ But other kinds of medical information raise precisely those issues—non-genetic tests can predict health risks; epigenetic changes can be hidden and predict propensity for disease; and many non-genetic factors, including many environmental stimulants or even epigenetic changes, are outside our control.¹⁹⁴ Moreover, if the concern is the immutability of genetic inheritance and the fact that our inheritance is outside of our control, how can we justify treating those with manifested genetic diseases differently from those who are merely at risk of genetic disease?¹⁹⁵ Even so, GINA and other genetics legislation draw such a line.

GINA's unique treatment of medical information raises more than problematic semantic challenges. It also presents practical problems of implementation and troubling inconsistent protections for similar kinds of information. With respect to the first problem, it is difficult for employers to comply with some of GINA's provisions. Although the ADA allows employers to seek the release of medical records of individuals to whom they have made a conditional offer of employment,¹⁹⁶ GINA limits this right by prohibiting the acquisition of genetic information. Mark Rothstein argues, however, that complying with this provision is 'infeasible'. Genetic information (whether one adopts the narrow or broad interpretation of this term) exists throughout the medical record, making it difficult or even impossible for health care providers to send medical records to employers devoid of any genetic information.¹⁹⁷

This difficulty implementing the GINA privacy protections reflects the fact that GINA provides a level of privacy protection with respect to genetic information that does not exist for health information under the ADA. In addition to prohibiting employers from discriminating based on genetic information, GINA prohibits them from acquiring genetic information, with some exceptions.¹⁹⁸ The ADA, in contrast, allows employers to access health records or require preemployment exams once a conditional offer of employment is made.¹⁹⁹ Although the ADA prohibits employers from discriminating on the basis of information about an employee's disability, employees may have difficulty determining or establishing whether employment decisions were made on that basis. GINA tries to limit this problem of proving discriminatory mindset by preventing employers from accessing genetic information in the first place. Why should genetic information be accorded such protection but not non-genetic medical information or information about manifested conditions (including genetic conditions)?

We should be especially troubled by this distinction because the temptation for employers to use information about a manifested condition would be just as great, if not greater than, the temptation to use information about a risk of a future illness that may not develop for years, or ever. The way that GINA treats family medical history only underscores this concern. To be sure, the biggest reason to include family medical history

¹⁹³ Suter, *supra* note 13, at 706–09.

¹⁹⁴ *Id.* at 712–15; Mark A. Rothstein, *GINA at Ten and the Future of Genetic Nondiscrimination Law*, 48 HASTINGS CTR. REP. 5, 6 (2018).

¹⁹⁵ Suter, *supra* note 13, at 715–21.

¹⁹⁶ 42 U.S.C. § 12112(d)(3).

¹⁹⁷ Rothstein, *Skin Deep*, *supra* note 38, at 9.

¹⁹⁸ See *supra* note 46 and accompanying text.

¹⁹⁹ 42 U.S.C. §§ 12112(d).

in the definition of ‘genetic information’ was to prevent employers from using indirect evidence to discern an employee’s genetic risks. But, as discussed earlier, another rationale to include medical information about family members (even if related through marriage or adoption) in the definition is because of concerns that employers might discriminate based on the potential health care costs associated with the family member’s illness. If those worries justify protection of information about family medical information, including information that does not in any way reveal the propensity of disease in the employee, it is not clear why an employee’s presymptomatic genetic information, but not information about an employee’s manifested condition, deserves privacy protection.

If one of GINA’s concerns was preventing employers from denying employment to someone because his wife’s multiple sclerosis may impose burdensome health care costs, shouldn’t we also be concerned about employers denying employment to someone because of potential health care costs associated with a manifested condition, genetic or otherwise, in *that individual*? That the ADA prohibits such discrimination if the condition constitutes a disability under the statute is an inadequate response. As noted above, because the ADA does not establish the same kind of privacy protection for health information that GINA provides for genetic information,²⁰⁰ it can be hard for plaintiffs to establish whether the prohibited discrimination under the ADA has occurred. Perhaps this problem could be avoided, and the implementation challenges of keeping genetic information out of medical records could be resolved, by more broadly limiting employer access to medical information post conditional offer, ie by treating all medical information more like genetic information.²⁰¹

On the other hand, there may be reasons to consider whether the privacy protections of GINA should be less absolute. GINA demands a ‘genome blind’ world where employers may never use genetic information for employment decisions.²⁰² The ADA, in contrast, treats health information quite differently. Employers may use health information for certain employment decisions, such as providing reasonable accommodation for otherwise qualified individuals with disabilities.²⁰³ The ADA is but one example of antisubordination approaches where employers can use information about employees to remedy or prevent discrimination and its affects.²⁰⁴

That GINA treats genetic information in such a manner is not in and of itself problematic. This unique treatment of information related to the protected status may, however, limit the potential of GINA to advance some of its underlying goals. Imagine the scenario that Jessica Roberts describes, where an employee has a genetic predisposition to carpal tunnel syndrome.²⁰⁵ If employers could use this genetic information to provide reasonable accommodations, in the way they can for individuals with disabilities under the ADA, for example, the employee’s chance of actually developing the condition might decrease.²⁰⁶ This outcome would be consistent with GINA’s goal of encouraging genetic testing so that people can improve their health. By treating genetic in-

²⁰⁰ See *supra* text accompanying notes 198–199.

²⁰¹ California has enacted legislation providing such protections. CAL. CIV. CODE §§ 56.20–56.245.

²⁰² Roberts, *GINA*, *supra* note 3, at 622.

²⁰³ 42 U.S.C. § 12112(b)(5)(A).

²⁰⁴ Areheart, *supra* note 11, at 711–12; Roberts, *GINA*, *supra* note 3, at 627–28.

²⁰⁵ Roberts, *GINA*, *supra* note 3, at 639.

²⁰⁶ *Id.*; Areheart, *supra* note 11, at 712.

formation differently from the way other antidiscrimination statutes treat information related to other protected groups, GINA might, to some extent, undermine its goal of encouraging the public to obtain the maximum benefits of genetic testing and related technologies.

CONCLUSION

As we have seen, GINA, like most legislation, is an imperfect statute. It represents compromises and trade-offs that arise when the underlying motivations are as varied and complex as the many actors who pushed for its enactment for 13 years. In addition, it most definitely did not solve the underlying problem of all genetics legislation; it did not provide a fully precise definition of the information it sought to protect. That it did not do so is not a function of Congressional incompetence or failure to understand the problem, but a failure of the mission itself—to try to distinguish what is ultimately incapable of precise distinction. Medical information is almost always genetic information to some extent; it is simply a question of the degree to which genetics plays a role. Trying to precisely carve out ‘genetic information’ definitionally is therefore an exercise doomed to inadequacy, if not failure.

But we exist in an imperfect world, where compromises and decisions must be made in the attempt to achieve certain objectives. We have special protections for genetic information, which reflect policy concerns, political motivations, and pragmatic goals. Whether GINA was actually necessary to prevent potential future genetic discrimination is hard to determine. Whether it has achieved its practical goal of decreasing the public’s fear of discrimination in order to motivate people to pursue genetic testing in clinical care and genomics research is even more uncertain.²⁰⁷ But this is the legislation we have, for better or worse.

Attempts by courts to narrow GINA’s scope ignore the compromises Congress made in defining ‘genetic information’ as well as the clear statutory language and broader policy goals of GINA. To the extent that it is problematic to carve out special protections for genetic information, the broader definition that GINA uses is preferable to a narrow definition because it moves us slightly closer toward treating genetic information like other medical information. This construction of ‘genetic information’, of course, is not a panacea. Nevertheless, courts must stop reliving the battle over the definition of ‘genetic information’. The broad definition prevailed. It is time for courts to recognize this in their application of GINA so that at least one of this statute’s goals can be achieved—uniform protections with respect to genetic information.

²⁰⁷ Sonia Suter, Address at The Genetic Information Non-Discrimination Act (GINA) at 10 Years, 112th AALS Annual Meeting: GINA’s 10-Year Checkup (Jan. 5, 2018) (presenting data from numerous studies showing that most people are unaware of GINA; many misunderstand the scope of its protections; and to the extent that people are aware of it, the data are mixed as to whether it allays or strengthens their fears).