

**THE GENETIC INFORMATION NONDISCRIMINATION ACT:  
THE LATEST DEVELOPMENTS**

*Presented by:*

**ALLISON L. BOWERS**, *Austin*  
Hutcheson Bowers

*Written by:*

**SHANNON HARPOLD HUTCHESON**, *Austin*  
Hutcheson Bowers

State Bar of Texas  
**24<sup>th</sup> ANNUAL**  
**ADVANCED EMPLOYMENT LAW COURSE**  
January 14-15, 2016  
Dallas

**CHAPTER 13**



## Allison L. Bowers



Allison Bowers is a founding partner of the Austin employment law firm of Hutcheson Bowers LLLP. Allison, rated AV-Preeminent by Martindale-Hubbell, is recognized by her peers for being "smart, honest, caring, and extremely capable." Born and raised in a small Texas town, Allison's approach to law reflects her grounded, practical roots. Allison graduated in the top of her class from the University of Texas with a Plan II major and was elected Phi Beta Kappa. A double Longhorn, Allison is a proud honors graduate of University of Texas School of Law where she

served on the Texas Law Review and was inducted into the Order of the Coif. After law school, she clerked for Judge Lee Yeakel, now Judge of the U.S. District Court for the Western District of Texas in Austin.

Before founding Hutcheson Bowers, Allison practiced law with Baker Botts LLP for over ten years. Allison is a frequent speaker on employment topics and has been a guest lecturer at her law school alma mater. Most recently, Allison served on the Board of Directors for the Austin Human Resources Management Association. Currently, Allison serves on the steering committee for Texas Minority Counsel Program and for the University of Texas School of Law. Allison's law firm is a member of the highly selective National Association of Women and Minority Owned Law Firms (NAMWOLF). Allison and her husband spend most of their time spoiling their only daughter and obsessing over Texas football.





**TABLE OF CONTENTS**

I. INTRODUCTION ..... 1

II. BACKGROUND AND RATIONALE FOR GINA ..... 1

III. HISTORY AND TIMELINE OF GINA AND ITS IMPLEMENTATION..... 3

IV. EARLY COMPLAINTS OF GINA VIOLATIONS AND ENSUING LITIGATION..... 3

V. ENTITIES BOUND BY GINA ..... 4

VI. GENETIC INFORMATION, DEFINED..... 5

    A. The Act’s definition ..... 5

    B. Genetic tests ..... 5

    C. Family members whose information is included ..... 5

    D. The exclusion for the employee’s non-genetic information..... 6

    E. Non-genetic “genetic information” ..... 6

VII. EMPLOYERS’ AFFIRMATIVE DUTIES UNDER GINA ..... 7

    A. Recordkeeping and Confidentiality Requirements..... 7

    B. Notice Requirements ..... 8

VIII. GINA’S PROHIBITIONS AGAINST EMPLOYERS ..... 8

    A. Adverse Treatment Prohibited ..... 8

    B. Retaliation Prohibited..... 9

    C. Acquisition of Genetic Information Prohibited..... 10

        1. Type of acquisition covered ..... 10

        2. Inadvertent, Deliberate, or somewhere in between?..... 10

IX. GINA PROCEDURES AND REMEDIES ..... 11

X. SPECIFIC WORKPLACE ISSUES ARISING UNDER GINA..... 12

    A. Wellness Programs, threatened ..... 12

    B. Forensic Testing in the Workplace..... 13

XI. CONCLUSION ..... 14



# THE GENETIC INFORMATION NONDISCRIMINATION ACT: THE LATEST DEVELOPMENTS

## I. INTRODUCTION

The Genetic Information Nondiscrimination Act (“GINA”), touted as the first civil rights act of this century,<sup>1</sup> was Congress’s response to the dramatic scientific advances of the last two decades.

The full sequence of the Human Genome was not fully mapped and published until as recently as 2003.<sup>2</sup> With genetic science flourishing, a person’s diseases, disorders, and other medical and psychological conditions could be increasingly traced to—and predicted from—their genetic makeup.

These developments provoked fears that such knowledge could be abused. As Congress recognized, those developments “give rise to the potential misuse of genetic information to discriminate in health insurance and employment.”<sup>3</sup> In passing GINA, Congress therefore sought to “protect the public from discrimination and allay their concerns about the potential for discrimination, thereby allowing individuals to take advantage of genetic testing, technologies, research, and new therapies.”<sup>4</sup>

GINA covers a broader range of behavior than the prohibitions included in previous civil-rights legislation. Despite its name and purpose, the Act prohibits more than just discrimination on the basis of a person’s genetic information. It also prohibits *acquiring* such information. Though inadvertent acquisition is excluded from the statute’s prohibitions, regulations have made it clear that no specific intent to acquire genetic information is required to show a violation,

<sup>1</sup> Sen. Olympia J. Snowe, S. 358, 153 CONG. REC. S846, S846 (Jan. 22, 2007) (quoting Senator Gregg).

<sup>2</sup> An Overview of the Human Genome Project, NATIONAL HUMAN GENOME RESEARCH INSTITUTE, <http://www.genome.gov/12011238> (last accessed November 12, 2015).

<sup>3</sup> An Act to prohibit discrimination on the basis of genetic information with respect to health insurance and employment, H.R. 493, 110th Cong., Pub. L. 110–233, § 1, 122 Stat. 881 (May 21, 2008), *as amended by* Pub. L. 111–256, § 2(j), 124 Stat. 2644 (Oct. 5, 2010), *codified at* 42 U.S.C. 2000ff.

<sup>4</sup> *Id.*

<sup>5</sup> 75 FR 68911, 68913 (Nov. 9, 2010).

<sup>6</sup> The Act passed the Senate with a 95 to 0 vote. S. 358, 154 CONG. REC. S3363, S3374 (April 24, 2008). It then passed the House of Representatives by a vote of 414 to 1. H.R. 493, 154 CONG. REC. H2961, H2979 (May 1, 2008).

<sup>7</sup> Hon. Louise Slaughter, H.R. 493, 153 CONG. REC. E120, E120 (Jan. 16, 2007).

either.<sup>5</sup> An employer obtaining medical information from an employee for an otherwise benign purpose should be aware of the strict protections in GINA.

## II. BACKGROUND AND RATIONALE FOR GINA

GINA was enacted in 2008 with bipartisan support and negligible opposition.<sup>6</sup> Although some allegedly criticized the legislation as “a solution in search of a problem,”<sup>7</sup> Congress identified several threats to the American people from the use of genetic information. First, Congress identified the country’s history of sterilization laws to “correct” apparent genetic traits or tendencies, which were passed in a majority of States by 1981.<sup>8</sup> This “history of sterilization laws by the States based on early genetic science, compel[ed] Congressional action in this area.”<sup>9</sup> Second, Congress cited the nation’s history of having used genetic information to discriminate on the basis of race. For example, before federal law intervened, American employers previously were permitted to require testing for sickle-cell anemia, and specific states intensified the situation by creating mandatory testing for this disease that primarily impacts African Americans.<sup>10</sup> Because “some genetic traits are most prevalent in particular groups, members of a particular group may be stigmatized or discriminated against as a result of that genetic information.”<sup>11</sup>

Third, the congressional findings to support GINA cited to one particular case of employer genetic testing, in which a medical research institution tested employees’ blood and urine upon hiring them without their knowledge and, in some cases, in a discriminatory

<sup>8</sup> The congressional findings explained that “[m]any of these State laws have since been repealed, and many have been modified to include essential constitutional requirements of due process and equal protection.” Pub. L. 110–233, § 2, 122 Stat. 881 (May 21, 2008), *as amended by* Pub. L. 111–256, § 2(j), 124 Stat. 2644 (Oct. 5, 2010), *codified at* 42 U.S.C. 2000ff.

<sup>9</sup>

*Id.*

<sup>10</sup> The congressional findings specified that “[t]his form of discrimination was evident in the 1970s, which saw the advent of programs to screen and identify carriers of sickle cell anemia, a disease which afflicts African-Americans. Once again, State legislatures began to enact discriminatory laws in the area, and in the early 1970s began mandating genetic screening of all African Americans for sickle cell anemia, leading to discrimination and unnecessary fear.” Pub. L. 110–233, § 3, 122 Stat. 881 (May 21, 2008); *codified at* 42 U.S.C. 2000ff.

<sup>11</sup> *Id.*

manner.<sup>12</sup> The Ninth Circuit in this 1998 opinion, *Bloodsaw v. Lawrence Berkeley Laboratory*, found a fact issue as to whether the testing violated the employees' constitutional right to privacy because of the employees' lack of consent to the testing and also upheld their Title VII claim because the tests were administered based on employees' race and gender.<sup>13</sup>

In fact, the two frequently mentioned precautionary tales involving employer genetic testing resulted in successful outcomes for the employees—even without the benefit of GINA's passage. The *Norman-Bloodsaw* case ended in a \$2.2 million settlement for the plaintiffs after the Ninth Circuit's favorable ruling on summary judgment.<sup>14</sup> The employees subject to genetic testing performed by Burlington Northern Santa Fe Railroad were vindicated, too, in the first lawsuit brought by the EEOC on this issue. Without notice to employees, Burlington was testing for a rare genetic condition that causes carpal tunnel syndrome, and was also screening for medical conditions such as diabetes and alcoholism.<sup>15</sup> The result of that suit, which was based on EEOC's claim of ADA violations, was also a settlement of up to \$2.2 million for the affected employees.<sup>16</sup>

In both of these cases, the conduct was especially egregious because the testing was performed

surreptitiously. *Bloodsaw*, though ruling in favor of the employees, necessarily left a gap that was not covered until the passage of GINA. At that point, the existing constitutional and statutory schemes did not protect employees subjected to medical testing, *as long as they were informed* of the nature of the testing, nor did they prohibit testing if the employer had performed tests of all employees in a nondiscriminatory manner. Though finding due-process and Title VII violations, the court correctly reasoned that “[t]here would of course be no violation if the testing were authorized, or if the plaintiffs reasonably should have known that the blood and urine samples they provided would be used for the disputed testing and failed to object.”<sup>17</sup>

As reflected in GINA's legislative findings, in Congress's publicized purpose for the bill, and the rhetoric among those promoting it, the bill focused on the threat of employers' discriminatory treatment of employees, and was accompanied by the argument that “[d]iscrimination based on genetics is just as wrong as discrimination based on race or gender.”<sup>18</sup> The bill's supporters frequently cited Americans' reluctance to undergo genetic testing—testing that could otherwise provide them with better healthcare—simply because the results could be used for discriminatory purposes against them by their insurer or employer.<sup>19</sup> The bill as

<sup>12</sup> *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1264–66 (9th Cir. 1998). Mark Rothstein notes the irony of the Lawrence Berkeley Laboratory as the seminal worst-case scenario for genetic testing. The employer was a national laboratory operated under contract with the Department of Energy, one of the two federal agencies completing the Human Genome Project. Cynthia Nance et al., *Discrimination in Employment on the Basis of Genetics: Proceedings of the 2002 Annual Meeting*, Association of American Law Schools Section on Employment Discrimination Law, 6 EMP. RTS. & EMP. POL'Y J. 57, 74 (2002).

<sup>13</sup> *Norman-Bloodsaw*, 135 F.3d at 70 (“it goes without saying that the most basic violation possible involves the performance of unauthorized tests — that is, the non-consensual retrieval of previously unrevealed medical information that may be unknown even to plaintiffs.”); *id.* at 1272–73 (“the employment of women and blacks at Lawrence was conditioned in part on allegedly unconstitutional invasions of privacy to which white and/or male employees were not subjected”). For example, the employer tested only women for pregnancy and only African Americans for sickle-cell anemia.

<sup>14</sup> Elizabeth Pendo, *Race, Sex, and Genes at Work: Uncovering the Lessons of Norman Bloodsaw*, 10 HOUS. J. HEALTH L. & POL'Y 227, 246 (2010) (citing Pamela A. MacLean, *Lawrence Labs Reaches 2.2M Accord in Biological Privacy Case*, L.A. DAILY J., Dec. 10, 1999, at 1.)

<sup>15</sup> EEOC, *Railway Settle ADA-Based Genetic-Testing Case for \$2.2 Million* *EEOC v. Burlington N. and Santa Fe Ry. Co.*, 16 ANDREWS EMP. LITIG. REP. 6 (2002).

<sup>16</sup> *EEOC And BNSF Settle Genetic Testing Case Under Americans With Disabilities Act*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/newsroom/release/5-8-02.cfm> (last accessed Nov. 12, 2015).

<sup>17</sup> *Norman-Bloodsaw*, 135 F.3d at 1270. The court also held that the employer's conduct did not violate the Americans with Disabilities Act (“ADA”). *Id.* at 1274.

<sup>18</sup> Sen. Edward Kennedy, S.B.358, 153 CONG. REC. S846, S847 (Jan. 22, 2007) (arguing that, under GINA, “[e]mployers cannot fire or refuse to hire persons because of their genetic characteristics.”) Despite this rationale, it was questionable before GINA's passage as to whether the threat of discrimination was well-founded, given that employers would be unlikely to find it cost-efficient to perform genetic testing of its employees. Genetic testing is expensive, while the results would only indicate a probability, rather than a certainty, that the employee would ultimately contract the disease identified by the test. Mark Rothstein, *Discrimination in Employment on the Basis of Genetics: Proceedings of the 2002 Annual Meeting*, Association of American Law Schools Section on Employment Discrimination Law, 6 EMP. RTS. & EMP. POL'Y J. 57, 74 (2002).

<sup>19</sup> *Id.* (“patients fear that undergoing genetic tests may lead to disqualification from future insurance coverage, or that an employer will fire them or deny a promotion based on the results of a genetic test. The consequence is that many

enacted, however, ultimately covered more behavior than just discriminatory treatment.

### III. HISTORY AND TIMELINE OF GINA AND ITS IMPLEMENTATION

President Bush signed GINA into law on May 18, 2008.<sup>20</sup> The statute became effective 18 months after this date, thus applying to employers beginning in November 2009.<sup>21</sup>

The EEOC began the rulemaking process to implement GINA in March 2009 by proposing substantive rules, which were subject to a mere 43 comments from the public.<sup>22</sup> Because the statute involved technical concepts that were outside the expertise of the EEOC, the EEOC staff also received technical assistance from the institute within the National Institutes of Health responsible for decoding the human genome.<sup>23</sup> Following some modifications in response to the notice-and-comment process, the final version of these substantive rules was issued, becoming effective on January 10, 2011.<sup>24</sup>

Later, in June 2011, EEOC proposed to amend its recordkeeping regulations so that employers' recordkeeping requirements of Title VII and ADA would apply to GINA charges as well.<sup>25</sup> The final rules pertaining to recordkeeping were published in February 2012 and became effective on April 3, 2012.<sup>26</sup>

### IV. EARLY COMPLAINTS OF GINA VIOLATIONS AND ENSUING LITIGATION

From the statute's inception through 2014, EEOC resolved around 1200 claims for employer GINA

---

Americans are choosing not to be tested, and are declining to participate in clinical trials so important for the development of new treatments.”); Hon. Louise Slaughter, H.R. 493, \_\_\_ Cong. Rec. E120, E120 (Jan. 16, 2007) (“40 percent of participants surveyed felt genetic testing was not a good idea for fear that health insurance companies might deny or drop them from their insurance plan.”);

<sup>20</sup> 74 Fed. Reg. 63981, 63981 (Dec. 7, 2009).

<sup>21</sup> Pub. L. 110-233, tit. II, § 213, 122 Stat. 920 (May 21, 2008).

<sup>22</sup> 75 Fed. Reg. 68912, 68913 (Nov. 9, 2010). In May 2009, the EEOC also proposed administrative and procedural changes to existing rules to include references to the new statute. These nonsubstantive rule amendments became effective in January 2010. See 74 Fed. Reg. 63981, 63981 (Dec. 7, 2009).

<sup>23</sup> 75 Fed. Reg. 68912, 68913 (Nov. 9, 2010).

<sup>24</sup> *Id.* at 68912.

<sup>25</sup> See 76 Fed. Reg. 31892.

<sup>26</sup> 77 Fed. Reg. 5396 (Feb. 3, 2012).

violations.<sup>27</sup> Of those, almost 1000 were either administratively closed or ended in findings by the EEOC that there was no reasonable cause for the claim.<sup>28</sup> The remaining claims ended with a successful outcome for the employee: 100 having resulted in settlements, 45 concluding through the employee's withdrawal of the charge in exchange for receipt of the desired benefits, and approximately 100 more that were found by the EEOC to have been supported by reasonable cause.<sup>29</sup> Employees received a total of \$4.48 million in monetary benefits as a result of their EEOC-filed GINA charges, which does not include any payments recovered through litigation.<sup>30</sup>

Clearly at this point in history genetic discrimination still plays a relatively small role in the employment-discrimination landscape. In contrast to the 1400 genetic-discrimination claims received by the EEOC since GINA's enactment, employees submitted nearly 170,000 claims of racial discrimination during that same time period.<sup>31</sup>

Employees whose claims are not resolved before the EEOC can turn to the courts for a remedy.<sup>32</sup> With less than four years of history behind us of applying GINA's statutory and administrative scheme, there are now a small but growing number of court opinions that illustrate the Act's practical application to the workplace. Those cases are incorporated into the substantive analysis below. The EEOC has also responded to uncertainties in GINA's regulatory scheme by publishing informal letters and other public guidance. Many of those publications will be referenced below, but those searching for answers to specific

<sup>27</sup> *Genetic Information Non-Discrimination Act Charges FY 2010 – 2014*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/statistics/enforcement/genetic.cfm>, last accessed Dec. 15, 2015 (includes concurrent charges with Title VII, ADEA, ADA, and EPA). Employees submitted nearly 1400 claims during this time period, but only 1200 have been resolved by the EEOC. *Id.*

<sup>28</sup> *Id.*

<sup>29</sup> *Id.* A reasonable cause determination is reached when the EEOC “believes that discrimination occurred based upon evidence obtained in investigation.” See *Definition of Terms*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/statistics/enforcement/definitions.cfm>, last accessed Dec. 15, 2015.

<sup>30</sup> *Id.*

<sup>31</sup> *Race-Based Charges FY 1997– FY 2014*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/statistics/enforcement/race.cfm>, last accessed Dec. 15, 2015.

<sup>32</sup> See 42 U.S.C. § 2000ff-6.

questions concerning GINA's interpretation can access the developing database of EEOC guidance posted on the Commission's website.<sup>33</sup>

## V. ENTITIES BOUND BY GINA

GINA applies to employers, employment agencies, labor organizations, and health insurers: Title I of GINA is devoted to the restrictions on health insurers, while Title II pertains to employers, employment agencies, and labor organizations. This article focuses on GINA's impact on employers specifically.

The entities covered by GINA are the same employers to which Title VII of the Civil Rights Act of 1964 ("Title VII") applies.<sup>34</sup> This means that, to qualify as an employer that is bound by GINA, the entity must be "engaged in an industry affecting commerce" and have 15 or more employees "for each working day in each of twenty or more calendar weeks in the current or preceding calendar year."<sup>35</sup> Additionally, like Title VII, GINA excludes from its restrictions the federal government and private membership clubs subject to Section 501(c) tax-exempt status.<sup>36</sup>

Some state and federal governmental entities are specifically included as employers subject to GINA's restrictions, though it is unlikely that claims against a state entity are actionable because of Eleventh Amendment immunity.<sup>37</sup>

Hospitals and other health-care entities are included as GINA "employers" as well, though the regulations specify that its protections do not apply while treating an employee as a patient.<sup>38</sup> The risks of a health-care employer treating an employee internally have already been demonstrated by a case in which an

EMT company sent its employee to its own urgent-care facility, an independent contractor, for a medical exam.<sup>39</sup> The plaintiff then brought a GINA claim that survived summary judgment because the employer ended up inadvertently receiving and viewing his family medical history following the exam.<sup>40</sup> This case suggests that a health-care employer should create protocols for screening off any genetic information obtained by the medical professionals treating an employee so that it is maintained separately from the individuals or department responsible for supervising each given employee.

GINA's definition of "employer" includes "any agent of" the entity.<sup>41</sup> The statute does not define the term "agent," but the term will likely be interpreted liberally. One court held as a matter of law that, where an outside physician handled the local fire department's employee physicals, the physician's act of adding a question to the paperwork that included family medical history qualified him as an "agent" of the fire department, even where no employment or other formal relationship existed.<sup>42</sup> And where an employer contracted with a vendor, Cigna, to conduct its fitness-for-employment exams, the court held the employer was fully liable for the medical forms' request for genetic information—despite Cigna alone having drafting and administering them—such that Cigna was not an indispensable party to the suit.<sup>43</sup>

An employer's agent is thus bound by the statute's requirements and prohibitions. This does not mean, however, that the agent of the employer can be held individually liable. The first case to address individual liability under GINA decided that Title VII's precedent

<sup>33</sup> Approximately twenty informal discussion letters published by EEOC concerning GINA are indexed at <http://www.eeoc.gov/eeoc/foia/letters> (last accessed December 15, 2015). Other guidance, including a question and answer document concerning small business bound by GINA, can be found at <http://www.eeoc.gov/laws/types/genetic.cfm> (last accessed Dec. 15, 2015).

<sup>34</sup> See 42 U.S.C. § 2000ff(2)(B)(i) (referencing § 2000e(b)).

<sup>35</sup> 42 U.S.C. § 2000e(b).

<sup>36</sup> *Id.*

<sup>37</sup> *Id.* § 2000ff(2)(B)(ii)–(v). The first court to analyze state liability under GINA concluded that, though Congress intended to abrogate state agencies' immunity, it did not effectively do so because the statute was not a valid exercise of its congressional power. *Culbreth v. Wash. Metropolitan Area Transit Auth.*, 10-cv-3321, 2012 WL 959385 (D. Md. Mar. 19, 2012). The court held the "legislation is not congruent or proportional to the injury" committed by the states "[b]ecause there is no evidence of a pattern or practice of discrimination by state employers on the basis of genetics." *Id.* (citing Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination*

Act, 63 VAND. L. REV 439, 486 (explaining "that GINA most likely would not satisfy the Court's congruence and proportionality test because of the limited evidence of existing genetic-information discrimination.")).

<sup>38</sup> 29 C.F.R. § 1635.1(b) ("This part does not apply to actions of covered entities that do not pertain to an individual's status as an employee . . . . For example, this part would not apply to [a] medical examination of an individual for the purpose of diagnosis and treatment unrelated to employment, which is conducted by a health care professional at the hospital or other health care facility where the individual is an employee.")

<sup>39</sup> *Maxwell v. Verde Valley Ambulance Co. Inc.*, No. CV-13-08044, 2014 WL 4470512 (D. Ariz. Sep. 10, 2014).

<sup>40</sup> *Id.*

<sup>41</sup> *Id.* § 2000e(b); see § 2000ff(2)(B)(i).

<sup>42</sup> *Lee v. City of Moraine Fire Dep't*, Case No. 3:13-cv-222, 2015 WL 914440 (S.D. Ohio Mar. 3, 2015).

<sup>43</sup> *EEOC v. Cummins Power Generation Inc.*, No. 14-cv-3408, 2015 WL 5697330 (D. Minn. Sep. 28, 2015).

was determinative because GINA had adopted its definition of “employer.”<sup>44</sup> Under Title VII, liability does not extend to individual employees in their individual capacities; rather, the language including the employer’s “agents” simply operates to create an employer’s *respondeat superior* liability for acts of its employee.<sup>45</sup> It thus appears that, as in Title VII, individual liability will not attach to employees who have committed GINA violations.

## VI. GENETIC INFORMATION, DEFINED

### A. The Act’s definition

“Genetic” information under GINA extends beyond the common-sense meaning of the word. The statute’s definition includes:

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.<sup>46</sup>

Information about the individual’s sex or age is explicitly excluded from the definition,<sup>47</sup> along with information about race or ethnicity that is not derived from a genetic test.<sup>48</sup>

### B. Genetic tests

A “genetic test” under the statute is “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes” and excludes “an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes.”<sup>49</sup>

The EEOC consulted with the National Human Genome Research Institute to develop additional

guidance regarding this term<sup>50</sup> and has rendered regulations providing examples of what is, and what is not, a genetic test. Many of the most commonly known genetic tests are identified as examples, such as: tests identifying the BRCA1 or BRCA2 breast-cancer gene, cystic fibrosis, sickle-cell anemia, or fragile X; amniocentesis or other fetal testing; DNA testing associated with information about ancestry or even paternity tests; and tests to determine an individual’s genetic predisposition to alcoholism.<sup>51</sup> A few examples of what are not covered: tests for viruses that are not composed of genetic material, for infectious and communicable diseases that may be transmitted through food handling; blood counts; cholesterol tests; and liver-function tests.<sup>52</sup> Tests for the presence of alcohol or illegal drugs in an individual’s system are also explicitly excluded as not genetic.<sup>53</sup>

In one of the few cases to apply the “genetic test” definition, the federal district court relied on the EEOC’s nonbinding guidelines to confirm that a positive HIV diagnosis did not qualify as a protectable “genetic test” under GINA.<sup>54</sup>

### C. Family members whose information is included

GINA’s protections extend not only to the employee’s genetic information, but to information regarding the employee’s family. The term “family members” as used in GINA covers a wide range of individuals, including the employee’s dependent as defined by ERISA’s insurance coverage provisions and any other individual up to a “fourth-degree relative” of the employee or its dependent.<sup>55</sup> Because of the category of individuals that are dependents for purposes of insurance coverage, even an adopted child or stepchild is therefore considered a dependent, along with his or her extended relatives, despite the lack of

<sup>44</sup> *Wright v. Stonemor Partners LLP.*, 2012 WL 4006120 (W.D.N.C. 2012).

<sup>45</sup> *Lassau v. S. Food Serv., Inc.*, 159 F.3d 177, 181 (4th Cir. 1998) (citing *Grant v. Lone Star Co.*, 21 F.3d 649, 653 (5th Cir.1994); *Williams v. Banning*, 72 F.3d 552, 554 (7th Cir.1995); *Smith v. St. Bernards Reg’l Med. Ctr.*, 19 F.3d 1254, 1255 (8th Cir.1994); *Miller v. Maxwell’s Int’l. Inc.*, 991 F.2d 583, 588 (9th Cir.1993); *Haynes v. Williams*, 88 F.3d 898, 901 (10th Cir.1996); *Smith v. Lomax*, 45 F.3d 402, 403 n. 4 (11th Cir.1995)).

<sup>46</sup> 42 U.S.C. § 2000ff(4)(A).

<sup>47</sup> *Id.* § 2000ff(4)(C).

<sup>48</sup> 29 C.F.R. § 1635.3(c)(2).

<sup>49</sup> *Id.* § 2000ff(7).

<sup>50</sup> 75 Fed. Reg. 68912, 68914 (November 9, 2010).

<sup>51</sup> 29 C.F.R. § 1635.3(f)(2).

<sup>52</sup> *Id.* § 1635.3(f)(3).

<sup>53</sup> *Id.* § 1635.3(f)(4).

<sup>54</sup> *Hoffman v. Family Dollar Stores, Inc.*, 3:14-cv-00664-FDW-DCK, 2015 WL 1399988 (W.D.N.C. Mar. 26, 2015) (citing 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>) (“Although the EEOC guidelines are not binding on this Court, they “do constitute a body of experience and judgment to which courts and litigants may properly resort for guidance.”).

<sup>55</sup> 42 U.S.C. §2000ff(3).

shared genetic information between that person and the employee.<sup>56</sup>

EEOC has implemented specific regulations identifying how distant a family member must be to be included in GINA's definition. Fourth-degree relatives under the regulations, for example, "include[] an individual's great-great-grandparents, great-great-grandchildren, and first cousins once-removed (i.e., the children of the individual's first cousins)."<sup>57</sup>

#### D. The exclusion for the employee's non-genetic information

GINA carves out from liability an employer's "use, acquisition, or disclosure of medical information *that is not genetic information about a manifested disease, disorder, or pathological condition*" of the employee herself.<sup>58</sup> Courts have held that a plaintiff's mere allegation of a given medical condition, such as hyperthyroidism, does not render it protectable without a specific basis for rendering it "genetic information."<sup>59</sup> One court has broadly stated, when concluding that an employee's allergies did not trigger GINA's protections, that "[d]iscrimination based on a condition, as opposed to "genetic information," is not covered by GINA.<sup>60</sup>

#### E. Non-genetic "genetic information"

The same carve-out does not apply to a family member's medical conditions, according to a strict reading of the statute. Though "manifestation of a disease or disorder" in a family member would often extend beyond the plain meaning of an employee's "genetic" information, there apparently is no defense under the statute or regulations that would exclude non-inheritable diseases or disorders of a family member.

Public commenters raised this concern to the EEOC while the regulations were being drafted, asking the EEOC to add terms that would limit protection only to those diseases that are "inheritable."<sup>61</sup> The Commission declined to do so, both because of a desire to comport with the statutory terms and because of "compliance and enforcement problems" that would ensue if an employer or investigator were required to determine whether each disease or disorder is inheritable.<sup>62</sup> The EEOC further registered its "doubts that questions about whether a family member has a cold, the flu, or similar conditions will often result in charges being filed under GINA."<sup>63</sup>

Maybe not often. But a litigious employee who is following the letter of the law can lodge a nonfrivolous claim from such facts. An employer's response to an employee's exposure to a contagious disease from her family, for example, including its failure to keep such information confidential, can ultimately become the focus of employment litigation.

Employees have begun testing this language. One federal district court found a genuine issue of material fact as to whether an employee's disclosure of his grandfather's history of cancer, without more, amounted to "genetic information."<sup>64</sup> In declining to grant summary judgment for the plaintiff, the court noted that his claim concerned his injured leg, not cancer, and that the doctor's notes indicated that his family history was "unremarkable."<sup>65</sup> But the court similarly denied the defendant's motion, reasoning that Congress included family medical history in the definition because of the

<sup>56</sup> See 29 U.S.C. § 1181(f)(2), referenced in 42 U.S.C. § 2000ff(3). The regulations specify the inclusion of children adopted or placed for adoption. 29 C.F.R. § 1635.3(a)(1)

<sup>57</sup> 29 C.F.R. § 1635.3(a)(2)(iv).

<sup>58</sup> 42 U.S.C. § 2000ff-9 (emphasis added).

<sup>59</sup> *Bell v. PSS World Med., Inc.*, No. 3:12-cv-381, 2012 WL 67661660 (M.D. Fla. Dec. 7, 2012) (unpublished) (holding because "Plaintiff has failed to provide any basis, factual or otherwise, for the Court to reasonably infer that her hyperthyroidism . . . equate[s] to genetic testing and/or genetic information, Plaintiff has failed to properly allege a valid claim under GINA") (citing *Graves v. Brookfield Suites Hotel & Convention Ctr.*, No. 11-CV-01060, 2012 WL 3941774, at \*1 (E.D. Wis. Sept. 10, 2012) (unpublished); *Leone v. N. J. Orthopaedic Specialists, P.A.*, No. 11-3957, 2012 WL 1535198, at \*6 (D.N.J. Apr. 27, 2012) (unpublished); *Dumas v. Hurley Med. Ctr.*, 837 F. Supp. 2d 655, 666 (E.D. Mich. 2011)).

<sup>60</sup> *Jacobs v. Donnelly Comm'ncs*, No. 1:13-cv-980-WSD, 2013 WL 5436682 (N.D. Ga. Sep 26, 2013) (plaintiff

"alleges, at most, that Defendants discriminated against Plaintiff because of her allergies, which Plaintiff alleges to be a genetic condition.) Similarly, where an employee alleged she was passed over for training because of her frequent doctor's appointments to attend to her genetic blood disorder, her GINA claim was dismissed with leave to amend because "her allegation fails to plausibly support the theory that [the employer] based his decision *on the results of genetic tests.*" *Leone v. N. Jersey Orthopaedic Spec., PA*, No. 11-3957, 2012 WL 1535198 (D.N.J. Apr. 27, 2012) (emphasis added).

<sup>61</sup> 75 Fed. Reg. 68912, 68915 (Nov. 9, 2010); see 29 C.F.R. § 1635.3 (defining "family medical history" as "information about the manifestation of disease or disorder in family members of the individual.")

<sup>62</sup> *Id.*

<sup>63</sup> *Id.*

<sup>64</sup> *Maxwell v. Verde Valley Ambulance Co. Inc.*, No. CV-13-08044, 2014 WL 4470512 (D. Ariz. Sep. 10, 2014).

<sup>65</sup> *Id.*

potential for employers to use such information as a “surrogate for genetic traits.”<sup>66</sup>

Two other courts have read the statute more narrowly, in favor of the employer. In one case, the federal district court decided that an interpretation of *genetic information* that included a family member’s non-hereditary disease “would give more protection to an employee’s family member’s information than to the actual employee’s information”—which the court deemed an “absurd result.”<sup>67</sup> The court thus granted summary judgment on the retaliation claim because the employee’s disclosure of her mother’s death from AIDS was not “genetic information.”<sup>68</sup>

In the second case, the court dismissed an employee’s GINA suit, which complained that he was terminated three days after completing a health questionnaire in which he disclosed that his wife had multiple sclerosis.<sup>69</sup> Contrary to the plain language of the statute—and despite the EEOC’s pronounced reluctance to force decisionmakers to decide which diseases are inheritable—the court relied on legislative history to support its conclusion that the family history of multiple sclerosis did not qualify as “genetic information.”<sup>70</sup> The court reasoned that “[t]he fact that [his] wife was diagnosed with multiple sclerosis *has no predictive value* with respect to [his own] genetic propensity to acquire the disease.”<sup>71</sup>

Congress did indeed intend to protect a wider class of information from an employee’s family history than from an employee’s own medical history, as evidenced by the broader “manifestation of disease and disorder” language that applies *only to family members’* information.<sup>72</sup> Rather than creating an “absurd result,” Congress’s expansive definition intended to account for the fact that genetic disorders can become known not just through genetic tests, but through conditions manifesting in family members, whether or not those conditions are confirmed through genetic testing.

<sup>66</sup> *Id.*

<sup>67</sup> *Conner-Goodgame v. Wells Fargo Bank, NA*, No. 2:12-cv-03426-IPJ, 2013 WL 5428448 (N.D. Ala. Sep. 26, 2013).

<sup>68</sup> *Id.* The court’s misunderstanding of GINA’s purpose continued when reasoning that her mother’s history could not qualify as *genetic information* because the employee “had no chance of acquiring HIV in the future as a result of her deceased mother’s AIDS. Any chance [she] had of acquiring HIV from her mother ended with Plaintiff’s infancy.” *Id.* This is, of course, true of all genetic information, which is fixed at an employee’s birth.

<sup>69</sup> *Poore v Peterbilt of Bristol, LLC*, 852 F. Supp. 2d 727, 729 (W.D. Va. 2012).

<sup>70</sup> *Id.* at 730–31 (“Congress included family medical history in the definition of ‘genetic information’ because it understood that employers could potentially use family medical history “as a surrogate for genetic traits.”)

Certainly the EEOC’s broad inclusion of “family medical history” as genetic information includes more than only proven hereditary disorders.<sup>73</sup> In contrast, employees’ own manifested diseases or disorders are not protectable if they are “not genetic information” because the ADA—not GINA—is the appropriate mechanism for such protection.<sup>74</sup>

Though a “predictive value” test appears nowhere in the Act, and indeed seems to contradict its plain language, courts will likely persist in seeking ways to restrict this expansive definition. The extent to which family medical history will be covered by GINA has yet to be fully resolved in the courts.

## VII. EMPLOYERS’ AFFIRMATIVE DUTIES UNDER GINA

### A. Recordkeeping and Confidentiality Requirements

GINA provides specific recordkeeping requirements for any genetic information that is possessed by an employer, and this requirement would presumably apply to information that was obtained before the statute’s enactment. The information “shall be maintained on separate forms and in separate medical files and be treated as a confidential medical record of the employee or member.”<sup>75</sup> Complying with the ADA’s requirements for confidential medical records will satisfy GINA.<sup>76</sup> The EEOC has noted that records stored or created in the course of complying with the Family Medical Leave Act (“FMLA”) may contain genetic information and that such information, once obtained, must be stored under these provisions.<sup>77</sup>

GINA imposes strict confidentiality rules as to employers’ treatment of genetic information. Exceptions are made for complying with an EEOC investigation, court order, certain research conducted with the Department of Health and Human Services, and the FMLA’s certification requirements.<sup>78</sup> Also,

<sup>71</sup> *Id.* at 731 (emphasis added).

<sup>72</sup> 42 U.S.C. § 2000ff(4)(A)(iii).

<sup>73</sup> 29 C.F.R. § 1635.3; *see, e.g.*, 75 Fed. Reg. 68912, 68915 (Nov. 9, 2010).

<sup>74</sup> The EEOC has clarified that “GINA prohibits discrimination based on genetic information and not on the basis of a manifested condition, while the ADA prohibits discrimination on the basis of manifested conditions that meet the definition of disability.” 75 Fed. Reg. 68912, 68931 (Nov. 9, 2010).

<sup>75</sup> 42 U.S.C. § 2000ff-5(a).

<sup>76</sup> *Id.* (citing 42 U.S.C. § 12112(d)(3)(B)).

<sup>77</sup> 78 Fed. Reg. 8833, 8870 (Feb. 6, 2013.)

<sup>78</sup> 42 U.S.C. § 2000ff-5(b).

disclosure of diseases can be made to public health agencies upon notice to the subject, but only if there is an imminent hazard of death or life-threatening illness.<sup>79</sup> Finally, under a strict interpretation of the statute, even disclosure of an employee's genetic information to the employee himself should only be made upon "written request."<sup>80</sup> HIPAA, however, trumps GINA's confidentiality rules in the sense that anything authorized under HIPAA is still permissible, despite the rigid rules of GINA.<sup>81</sup>

In one of the earliest GINA lawsuits to be successfully brought and then settled by the EEOC, seed and fertilizer companies ultimately agreed to pay \$187,500 for its genetic-discrimination violations, which included the employers' failure "to adequately maintain the confidentiality of the medical and genetic information, permitting such information to be unlawfully commingled with non-confidential personnel files."<sup>82</sup>

Note that, because "genetic information" includes information as seemingly benign as an employee's family member's contraction of common infectious diseases, the careful employer will want to train its employees on their treatment of such information. Though perhaps unlikely to result in litigation, a supervisor's email to several subordinates notifying them that a given employee will be absent while caring for his flu-stricken child could violate a rigid interpretation of GINA's confidentiality rules. Any number of other "disorders" suffered by their children or spouses, whether hereditary or not, that employees may otherwise typically discuss among themselves, such as insomnia, food allergies, or speech irregularities, will also presumably trigger GINA's broad confidentiality protections.

Another, perhaps unexpected, application of the confidentiality rules is to employees' *receipt of genetic services*. Because, for example, women are increasingly being referred for genetic counseling and testing during pregnancy to detect possible chromosomal abnormalities, it is common for a company's pregnant employees to miss work to attend to these appointments. The mere fact that an employee is receiving such

services is "genetic information" under GINA, and should be treated by an employer with the same degree of confidentiality as would be the final results of those or any other genetic test.<sup>83</sup>

The "genetic" information covered by GINA may often be exchanged casually, through oral conversations among employees and supervisors. The regulations specify that such orally exchanged information, though not required to be reduced to writing, is equally as protected by the confidentiality requirements.<sup>84</sup>

## B. Notice Requirements

Employers are now required to post notice of the GINA protections at conspicuous places in the workplace.<sup>85</sup> The EEOC's example poster, "EEO is the Law," that was previously required to be posted by covered employers, now contains the requisite GINA language. The newest version of the mandatory notice can be downloaded from EEOC's website.<sup>86</sup>

## VIII. GINA'S PROHIBITIONS AGAINST EMPLOYERS

The bulk of GINA's protections come in the form of specified acts that employers are prohibited from taking against employees. Most of these mimic the classic types of adverse employment acts prohibited under other civil-rights legislation, such as Title VII, that protects against racial and gender discrimination. The remainder of the prohibitions relate to an employer's unlawful acquisition of genetic information.

### A. Adverse Treatment Prohibited

GINA and its regulations render it unlawful for an employer to take the following specific acts on the basis of genetic information:

- (1) to fail or **refuse to hire**, or to **discharge**, an employee;<sup>87</sup>
- (2) "**otherwise to discriminate** against [an] employee with respect to the compensation, terms, conditions, or privileges of employment of the employee";<sup>88</sup>

(including obtaining, interpreting, or assessing genetic information), or genetic education.")

<sup>84</sup> *Id.* § 1635.9(a)(3).

<sup>85</sup> *Id.* § 1635.10(c).

<sup>86</sup> *EEO is the Law*, U.S. EQUAL OPPORTUNITY COMMISSION, <http://www1.eeoc.gov/employers/poster.cfm>, (last accessed Nov. 12, 2015).

<sup>87</sup> 42 U.S.C. § 2000ff-1(a)(1).

<sup>88</sup> *Id.*; see also 29 C.F.R. § 1635.4(a) (rendering it "unlawful for an employer to discriminate against an individual on the basis of the genetic information of the individual in regard to

<sup>79</sup> *Id.* at § 2000ff-5(b)(6).

<sup>80</sup> *Id.* at § 2000ff-5(b)(1).

<sup>81</sup> *Id.* § 2000ff-5(c).

<sup>82</sup> *EEOC v. All Star Seed*, No. CV13-07196 JAK (C.D. Cal. 2013); see *Press Release*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, <http://www1.eeoc.gov/eeoc/newsroom/release/11-10-14.cfm> (last accessed Dec. 21, 2015).

<sup>83</sup> See 29 C.F.R. § 1635.3(c)(1)(iv); see also *id.* § 1635.3(e) ("Genetic services means a genetic test, genetic counseling

- (3) “to **limit, segregate, or classify** the employees in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee”;<sup>89</sup>
- (4) or “**fail or refuse to refer for employment** any individual”<sup>90</sup> in a way that would deprive or tend to deprive the individual of employment opportunities or otherwise adversely affect the employee’s status;<sup>91</sup>
- (5) to “discriminate against any individual . . . in admission to, or employment in, any program established to provide **apprenticeship or other training** or retraining.”<sup>92</sup>

These prohibitions will sound familiar, as the wording was largely adopted from Title VII’s discrimination provisions.<sup>93</sup> Congress, however, explicitly declined to create a “disparate impact” GINA claim for employees.<sup>94</sup> Disparate-impact claims operate to prohibit those acts that are “fair in form, but discriminatory in operation.”<sup>95</sup> Without a disparate-impact GINA claim, then, an employer is presumably free to institute facially neutral job requirements that have a disproportionate impact on individuals possessing a certain class of genes, even if the requirement is unjustified by a legitimate business rationale.<sup>96</sup> This omission distinguishes GINA from Title VII and other civil-rights legislation, such as the ADEA and, most recently, the Fair Housing Act, in

---

hiring, discharge, compensation, terms, conditions, or privileges of employment.”).

<sup>89</sup> 42 U.S.C. § 2000ff-1(a)(2); *see also* 29 C.F.R. § 1635.5(a).

<sup>90</sup> 29 C.F.R. § 1635.5(a).

<sup>91</sup> 42 U.S.C. § 2000ff-1(a)(2); *see also* 29 C.F.R. § 1635.5(a).

<sup>92</sup> 29 C.F.R. § 1635.4(d).

<sup>93</sup> *See* 42 U.S.C. § 2000e-2(a); (d).

<sup>94</sup> *Id.* § 2000ff-7.

<sup>95</sup> *Texas Dep’t of Housing & Cmty. Affairs v. Inclusive Cmty. Project*, 576 U.S. \_\_\_, 8 (2015) (quoting *Griggs v. Duke Power Co.*, 401 U.S. 424 (1971)).

<sup>96</sup> A disparate-impact plaintiff typically must prove that an employer’s challenged practice has a “disproportionately adverse effect on minorities and [is] otherwise unjustified by a legitimate rationale.” *Id.* at 1.

<sup>97</sup> *See id.* at 7–11.

<sup>98</sup> William J. McDevitt, *I Dream of Gina: Understanding the Employment Provisions of the Genetic Information Nondiscrimination Act of 2008*, 54 VILLANOVA L. REV. 22 (2009).

which disparate-impact claims have either been created in the statute itself or implied by the Court.<sup>97</sup>

The omission of a disparate-impact claim appears to be a compromise, struck to ensure its passage.<sup>98</sup> Because Congress recognized that the developing science on genetic information required a closer assessment of the need for a disparate-impact claim, it called for a commission to study this issue.<sup>99</sup> The commission was designated to begin its work in May of 2014, and, at the time of this article, had not yet published its findings regarding the plausibility of, or need for, a genetic disparate-impact claim.

## B. Retaliation Prohibited

The Act includes a prohibition against retaliation that mirrors Title VII and the American with Disabilities Act’s retaliation provisions.<sup>100</sup> An employer may not “discriminate” against an individual “because such individual has opposed any act or practice made unlawful by this chapter or because such individual made a charge, testified, assisted, or participated in any manner in an investigation, proceeding, or hearing under this chapter.”<sup>101</sup>

Employers should expect that the precedent concerning retaliation under Title VII and the ADA will be adopted wholesale when resolving GINA suits.<sup>102</sup> This means that, even where the original discrimination claim was unsubstantiated, an employer’s adverse response to that empty claim can generate an actionable retaliation claim.<sup>103</sup> The EEOC has announced that, at

<sup>99</sup> 42 U.S.C. § 2000ff-7 (requiring the establishment of the Genetic Nondiscrimination Study Commission six years after the Act’s effective date).

<sup>100</sup> *Compare* 42 U.S.C. § 12203(a) *with* 42 U.S.C. § 2000ff-6(f).

<sup>101</sup> 42 U.S.C. § 2000ff-6(f).

<sup>102</sup> One of the first suits to address a GINA retaliation claim took this approach. *Conner-Goodgame v. Wells Fargo Bank, NA*, No. 2:12-cv-03426-IPJ, 2013 WL 5428448 (N.D. Ala. Sep. 26, 2013) (“Because GINA’s anti-retaliation provision tracks the language of Title VII’s anti-retaliation provision, the court has analyzed Plaintiff’s retaliation claim under Title VII’s framework for retaliation.”).

<sup>103</sup> *Facts about Retaliation*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, [http://www.eeoc.gov/laws/types/retaliation\\_considerations.cfm](http://www.eeoc.gov/laws/types/retaliation_considerations.cfm) (last accessed Dec. 20, 2015) (“Why is this so common? Why does a situation move from an unproven/unsubstantiated allegation to a later violation based on the manager’s response to the employee initiating a complaint? The simple answer is that individuals often seek to avenge a perceived offense. The desire to retaliate is a common human reaction, but when done by a management official because employees assert their right to challenge a perceived wrong, the retaliation can establish legal liability.”)

least among federal employees, retaliation is therefore the most frequently alleged discrimination claim and the “most common discrimination finding.”<sup>104</sup>

Employers should carefully rely on their counsel to instruct them when facing a situation in which an employee has raised a concern—either formally or informally and *whether or not the concern is valid*—regarding possible genetic discrimination.

### C. Acquisition of Genetic Information Prohibited

Unlike past civil-rights legislation, GINA prohibits more than just an employer’s adverse actions that are based on the protected classification. Beyond prohibiting discrimination, GINA prohibits the mere *acquisition* of genetic information.

#### 1. Type of acquisition covered

An employer cannot “request, require, or purchase genetic information with respect to an employee or a family member of the employee.”<sup>105</sup> There are limited exceptions for “inadvertent” receipt of the information, discussed below, including exceptions for an employer’s purchase of “commercially and publicly available” documents that include information about an employee’s family medical history.<sup>106</sup> Under narrow circumstances and with the authorization of the employee, the employer can also receive genetic information to monitor the biological effects of toxic substances in the workplace.<sup>107</sup>

Where an employer’s acquisition of genetic information does fall into one of the narrow exceptions, the information still may not be used as the basis of discrimination or other adverse employment actions.<sup>108</sup>

This prohibition on acquiring genetic information, and the broad accompanying definition of genetic information, is the portion of the Act that is most likely to catch employers off guard. Not surprisingly, the first GINA lawsuits that were filed and then settled by the

EEOC both concerned GINA’s “acquisition” prohibition. In those cases, the employer had the practice of sending its new hires for medical exams in which the employees were asked questions about their family medical history.<sup>109</sup> Because family medical history is considered “genetic information” under the Act, the EEOC considered these questions violations of GINA’s acquisition provision.

The settlements both resulted in substantial payouts. In the first case, the employer paid \$50,000 to one employee for the illegal family-history questions and for having rescinded her job offer once it suspected she had carpal tunnel syndrome.<sup>110</sup> In the second case, no discrimination was found, yet the consent decree required the employer to pay \$110,400 to be distributed to the 138 individuals who were asked for their genetic information.<sup>111</sup>

#### 2. Inadvertent, Deliberate, or somewhere in between?

In passing GINA, the consensus of the legislature seemed to be that the statute would bar employers’ behavior that was intentional and wilful. For example, one Senator contended during deliberations that “discrimination based on one’s genetic makeup involves actively looking for information on which to discriminate. Because it is so deliberate, one cannot even argue it was—on any level—subconscious or unintentional.”<sup>112</sup> But the few years since the Act’s passage have proven that not all receipt of genetic information by employers is “deliberate,” requiring a more careful parsing of what state of mind is required to amount to a violation. In fact, the EEOC has declared that an employer “may violate GINA *without a specific intent to acquire* genetic information,” and decided to remove the term “deliberate acquisition” from the regulations.<sup>113</sup>

The Act does exclude from prohibited acts an employer who “inadvertently requests or requires

<sup>104</sup> *Id.* (citing that between 42–53% of findings of discrimination among complaints filed by federal employees were based on retaliation).

<sup>105</sup> 42 U.S.C. § 2000ff-1(b).

<sup>106</sup> *Id.* §2000ff-1(b)(4). The exception for commercially available documents does not apply if the entity intended to obtain genetic information when accessing the document or anytime the employer accesses a media source through which it “is likely to acquire genetic information . . . such as Web sites and on-line discussion groups that focus on issues such as genetic testing of individuals and genetic discrimination.” 29 C.F.R. § 1635.8(b)(4)(iii)-(iv).

<sup>107</sup> *Id.* §2000ff-1(b)(5). There is also a narrow exception that applies for forensic purposes, but “only to the extent that such genetic information is used for analysis of DNA identification markers for quality control to detect sample contamination.” *Id.* § 2000ff-1(b)(6).

<sup>108</sup> *Id.* §2000ff-1(c).

<sup>109</sup> *See EEOC v. Fabricut, Inc.*, 13-CV-248-CVE-PJC (N.D. Okla. 2013); *EEOC v. Founders Pavilion, Inc.*, 13-CV-01438 (W.D.N.Y. 2013).

<sup>110</sup> *Press Release*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION (MAY 7, 2013) <http://www.eeoc.gov/eeoc/newsroom/release/5-7-13b.cfm> (last accessed Dec. 21, 2015).

<sup>111</sup> *Press Release*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION (JAN. 13, 2014) <http://www.eeoc.gov/eeoc/newsroom/release/1-13-14.cfm> (last accessed Dec. 21, 2015).

<sup>112</sup> Sen. Olympia J. Snowe, S.B.358, 153 Cong. Rec. S846, S846 (Jan. 22, 2007)

<sup>113</sup> 75 Fed. Reg. 68911, 68913 (Nov. 9, 2010) (emphasis added).

family medical history of the employee or family member of the employee.”<sup>114</sup> The EEOC has considered a range of scenarios in which employers may acquire genetic information, seeking to delineate them into those that are “inadvertent” and those that are not. For example, where an employee is subject to a medical exam related to employment, such as an exam to determine the employee’s fitness to work, the EEOC requires that the employer is under an *affirmative duty* to instruct the health-care provider *not to collect genetic information, including family medical history*, and “must take additional reasonable measures within its control if it learns that genetic information is being requested or required.”<sup>115</sup> What measures are “reasonable” depend on the given facts and circumstances, and may include halting use of the health-care provider who continues to ask for genetic information during the exams.<sup>116</sup>

Casual workplace conversations will inevitably include discussion of both an employee’s inheritable diseases and of family medical history, including ongoing diseases, disorders, and other genetic conditions possessed by an employee’s close family member. The EEOC has sought to classify such interactions into prohibited and permitted acts, though these types of interpersonal interactions are characteristically hard to place into clear categories. It has listed the following interactions by an employer’s supervisor or other agent as examples of “inadvertent” acquisition:<sup>117</sup>

- (A) Overhearing an employee’s conversation or receiving an unsolicited email about an employee’s family member from a co-worker

- (B) Asking a question in a casual conversation, including while expressing concern about an employee or her family member’s health (such as, “How’s your son feeling today” or “Did they catch it early?”). This type of general health inquiry is exempt as long as the questions are not “probing in nature,” which would render it likely that they will lead to genetic information.
- (D) Learning genetic information from a social media platform to which the employee had granted a supervisor access.<sup>118</sup>

Even if this acquisition is inadvertent, any resulting genetic information obtained is likely still subject to the remaining provisions of GINA, such as the confidentiality requirements.<sup>119</sup>

## IX. GINA PROCEDURES AND REMEDIES

Lawsuits filed under GINA require the same procedures and offer the same remedies as those created under Title VII.<sup>120</sup> This means that the EEOC and the Attorney General are primarily charged with enforcing GINA and that employees must timely exhaust their administrative remedies through the EEOC before filing suit.<sup>121</sup> As one court has recently confirmed, the plaintiff must specifically allege a genetic-information claim before the EEOC; making a related ADA claim will not effectively preserve his right to file suit.<sup>122</sup>

Damages under GINA are governed by the Civil Right’s Act’s Section 1981a.<sup>123</sup> Compensatory and punitive damages are therefore allowed, but subject to the caps set forth in that Section, which increase with the size of the employer.<sup>124</sup> Future pecuniary losses and

<sup>114</sup> *Id.* § 2000ff-1(b)(1).

<sup>115</sup> 29 C.F.R. § 1635.8(d). The EEOC creates an exception if the requested information was not likely to result in receipt of genetic information “(for example, where an overly broad response is received in response to a tailored request for medical information)”. *Id.* § 1635.8(b)(1)(i)(C).

<sup>116</sup> *Id.* (“Such reasonable measures may depend on the facts and circumstances under which a request for genetic information was made, and may include no longer using the services of a health care professional who continues to request or require genetic information during medical examinations after being informed not to do so.”)

<sup>117</sup> 29 C.F.R. 1635.8(b)(1)(ii).

<sup>118</sup> Where an employee alleged that he had posted information about his genetic disorder on his Facebook page that another employee had access to and frequently viewed, the GINA cause of action was dismissed for failure to state a claim because he failed to allege that this specific genetic information was viewed by that, or any other, employee. *Rusthoven v. Victor Sch. Dist. #7*, No. 14-170-M-DLC, 2014 WL 6460190 (D. Mont. Nov. 17, 2014).

<sup>119</sup> 42 U.S.C. § 2000ff-5(a).

<sup>120</sup> 42 U.S.C. § 2000ff-6(a)(1).

<sup>121</sup> *Id.*; see *id.* § 2000e-5(f)(1); 29 C.F.R. § 1635.10; *e.g. Ellie v. Sprint*, 2015 WL 5923364 (D. Md. October 07, 2015) (“GINA claims are subject to Title VII exhaustion requirements.”).

<sup>122</sup> *Macon v. Cedarcroft Health Servs., Inc.*, No. 4:12-CV-1481 2013 WL 1283865 (E.D. Mo. Mar. 27 2013); see also *Bowie v. Univ. of Md. Med. Sys.*, No. ELH-14-03216, 2015 WL 1499465 (D. Md. Mar. 31, 2015) (holding that, where the plaintiff checked both the “ADA” and “retaliation” boxes of the EEOC Charge form, this did not provide notice that was sufficient to satisfy exhaustion requirement for his GINA retaliation claim).

<sup>123</sup> 42 U.S.C. § 2000ff-6(a)(3).

<sup>124</sup> 42 U.S.C. § 1981a(b)(3) (setting limits on the amount per plaintiff that can be recovered for the “sum of the amount of compensatory damages awarded . . . for future pecuniary losses, emotional pain, suffering, inconvenience, mental anguish, loss of enjoyment of life, and other nonpecuniary

noneconomic damages, including punitives, cannot exceed those specific amounts, which start at \$50,000 per plaintiff for companies employing 100 employees or less.<sup>125</sup> The statute also allows for “any equitable relief” that the court deems appropriate, listing “reinstatement or hiring of employees, with or without back pay” as nonexclusive examples.<sup>126</sup>

The fees provisions from the Civil Rights Act’s Section 1988 also apply to GINA actions, such that the prevailing party may, in the court’s discretion, recover fees.<sup>127</sup> Though the statute purports to allow fees equally for any “prevailing party,” courts have applied a double standard to fee recovery under Section 1988,<sup>128</sup> and those two standards will surely apply to suits brought under GINA. Plaintiffs can recover fees even if they only partially succeed on their claims,<sup>129</sup> but a defendant cannot recover unless if the suit was “without foundation, unreasonable, frivolous, meritless, or vexatious.”<sup>130</sup>

## X. SPECIFIC WORKPLACE ISSUES ARISING UNDER GINA

### A. Wellness Programs, threatened

GINA carves out from an employer’s prohibition against acquisition of genetic information “health or genetic services” that the employer offers, including such services offered as part of a wellness program if:

1. the employee gives “prior, knowing, voluntary, and written authorization”;
2. only the professional provider receives any individually identifiable results;
3. the employer receives results only in aggregate terms that do not disclose the employees’ identities.<sup>131</sup>

---

losses, and the amount of punitive damages awarded under this section”).

<sup>125</sup> *Id.* § 1981a(b)(3)(A).

<sup>126</sup> *Id.* § 2000e(g)(1).

<sup>127</sup> 42 U.S.C. § 2000ff-6(a)(2) (citing 42 U.S.C. § 1988(b)).

<sup>128</sup> *Crawford v. W. Elec. Co., Inc.*, 614 F.2d 1300, 1321 (5th Cir. 1980).

<sup>129</sup> *Hensley v. Eckerhart*, 461 U.S. 424, 433 (1983).

<sup>130</sup> *Crawford*, 614 F.2d at 1321.

<sup>131</sup> 42 U.S.C. § 2000ff-1(b)(2); 29 C.F.R. § 1635.8(b)(2).

<sup>132</sup> ADA: Voluntary Wellness Programs & Reasonable Accommodation Obligations, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM’N, [http://www.eeoc.gov/eeoc/foia/letters/2013/ada\\_wellness\\_programs.html](http://www.eeoc.gov/eeoc/foia/letters/2013/ada_wellness_programs.html) (last accessed Dec. 22, 2015).

<sup>133</sup> *EEOC v. Orion Energy Sys., Inc.*, Case No. 14-1019 (E.D. Wis. filed Aug. 20, 2014); *EEOC v. Flambeau, Inc.*, Case No.

The EEOC has recently filed several lawsuits related to wellness programs that have put the legality of employer wellness programs into question. There are two primary issues arising under these programs. First, can the employer offer financial incentives or penalties in connection with these programs, and to what extent? Second, can the employer request a spouse’s medical information upon his or her participation in the wellness program without running afoul of the prohibition on acquisition of “family medical history”?

Both Congress and the EEOC have stepped forward to attempt to answer these questions.

EEOC initially expressed some skepticism about the legality of incentives and penalties in employee wellness programs. It warned in 2013, at least under the ADA’s requirements, that the Commission had not yet “taken a position on whether and to what extent a reward amounts to a requirement to participate, or whether withholding of the reward from non-participants constitutes a penalty, thus rendering the program involuntary.”<sup>132</sup> The EEOC later took a firm position on these programs, filing three lawsuits claiming employer wellness programs violated GINA because they offered incentives or penalties for the employers’, and in some cases, their spouses’, participation.<sup>133</sup> Two of the cases involved an employer’s requiring the employee to pay a reduced health-insurance premium upon participation in the wellness program, and another subjected the employees to disciplinary action for failure to participate.<sup>134</sup>

A group of Republican legislators responded to the EEOC’s harsh approach by introducing a bill in March of 2015 that would reverse the EEOC’s position.<sup>135</sup> The “Preserving Employee Wellness Programs Act” would allow wellness programs to provide incentives without violating GINA, as long as those incentives comply with

14-638 (W.D. Wis. filed Sept. 30, 2014); *EEOC v. Honeywell Int’l, Inc.*, Civil No. 14-4517 (D. Minn. filed Oct. 27, 2014).

<sup>134</sup> *See id.*; Kim Wilcoxon, *Is EEOC Wellness Program Litigation Making you Sick?*, LAW360 (Feb. 11, 2015), <http://www.law360.com/articles/619521/is-eeoc-wellness-program-litigation-making-you-sick> (last accessed Dec. 22, 2015). The EEOC’s position contradicted the Eleventh Circuit’s approach to these same types of programs, which had held that a charge on employees’ paychecks for refusing to participate in wellness programs did not amount to an ADA violation. *See Seff v. Broward Cnty.*, 691 F.3d 1221 (11th Cir. 2012).

<sup>135</sup> Eric S. Dreiband & Haley A. Wojdowski, *Proposed Wellness Plan Legislation Responds to Lawsuits Filed by the EEOC*, JONES DAY (Mar. 2015), [http://www.jonesday.com/proposed-wellness-plan-legislation-responds-to-lawsuits-filed-by-eeoc-03-19-2015/#\\_edn19](http://www.jonesday.com/proposed-wellness-plan-legislation-responds-to-lawsuits-filed-by-eeoc-03-19-2015/#_edn19) (last accessed Dec. 22, 2015).

the Public Health Service Act.<sup>136</sup> Under the Public Service Health Act, as amended by the Affordable Care Act, incentives are capped at “30 percent of the cost of the coverage” or up to 50 percent upon approval by the Secretaries of Labor, Health and Human Services, and the Treasury.<sup>137</sup> The 2015 bill is still under Committee consideration.<sup>138</sup>

The EEOC has also recently proposed regulations that would attempt to resolve the dispute. Its proposed rule would allow incentives for an employee’s or a spouse’s participation under limited circumstances, including an adoption of the 30% cap in the Public Health Service Act and Affordable Care Act, but would prohibit any inducements in exchange for the employee’s children’s health information.<sup>139</sup> The proposed regulations would also expressly permit medical information to be collected about a spouse who is voluntary participating in the wellness program without violating the family-medical-history acquisition prohibition in GINA.<sup>140</sup>

The EEOC has estimated that about half to two-thirds of the employers subject to GINA offer some type of wellness program.<sup>141</sup> The pending legislation and regulation would offer welcome relief to the many employers facing uncertainty about the law’s current status.

## B. Forensic Testing in the Workplace

GINA does not limit protected genetic information to only that information that would reflect an employee’s propensity for disease. An employer who collects genetic material for other purposes unrelated to genetic discrimination will still violate the Act. Specifically, GINA reflects no exception for an

employer’s collection of genetic material for forensic purposes, other than “for purposes of human remains identification.”<sup>142</sup>

An employer faced an impossible dilemma, then, when an unknown employee began repeatedly defecating in its warehouse.<sup>143</sup> To identify the perpetrator, the employer required the suspects to submit to cheek swabs, on which a genetic lab conducted forensic testing. The employees responded by suing for GINA violations.

In that case, the federal district court reasoned that there was simply no limitation in the Act to include only that information that reflects *propensity of disease*. Instead, GINA was intended, more generally, to provide a “national and uniform basic standard of unacceptable use of genetic information.”<sup>144</sup> The court held that the definition of “genetic test” was broad enough to cover the employer’s investigation and granted the employee’s motion for summary judgment on liability.<sup>145</sup> The jury ultimately awarded the employees \$2.25 million, including \$1.75 million in punitive damages, for the violation.<sup>146</sup>

The EEOC has faced the question, too, acknowledging that a forensic testing exception was neither raised during the regulations’ public-comment period nor considered on the record during the Act’s legislative passage.<sup>147</sup> Ultimately, though a forensic-testing carve-out “might well constitute a reasonable interpretation of the statutory exception,” the EEOC agreed that an employee forensic DNA analysis satisfied the Act’s definition of “genetic test,” thus violating GINA’s acquisition provision.<sup>148</sup>

Under the little guidance that is available to employers, then, the answer is clear—though perhaps

<sup>136</sup> *Id.*; see Preserving Employee Wellness Program Act, S. 620, 114th Cong. at § 3(a)(1) (“workplace wellness programs, or programs of health promotion or disease prevention offered by an employer or in conjunction with an employer-sponsored health plan, . . . shall not violate . . . the Genetic Information Nondiscrimination Act of 2008 . . . because such program provides any amount or type of reward . . . to program participants if such program complies with such section 2705(j) [of the Public Health Service Act]).

<sup>137</sup> *Id.*

<sup>138</sup> S. 620 – Preserving Employee Wellness Program Act, CONGRESS.GOV, <https://www.congress.gov/bill/114th-congress/senate-bill/620/all-actions-without-amendments> (last accessed Dec. 22, 2015).

<sup>139</sup> 80 Fed. Reg. 66853, 66856—57 (Oct. 30, 2015).

<sup>140</sup> *Id.* at 66858.

<sup>141</sup> *Id.* (“We estimate that there are approximately 782,000 employers with 15 or more employees subject to Title II of GINA 27 and, of that number, one half to two thirds (391,000 to 521,333) offer some type of wellness program.”)

<sup>142</sup> 42 U.S.C. § 2000ff-1(b)(6).

<sup>143</sup> *Lowe v. Atlas Logistics Grp. Retail Servs., LLC*, 1:13-CV-2425-AT (N.D.Ga. May 5, 2015).

<sup>144</sup> *Id.*

<sup>145</sup> *Id.*

<sup>146</sup> Mark Joseph Stern, Jury Awards \$2.2 Million to Employees Over DNA Tests in “Devious Defecator” Case, SLATE (Jun. 23, 2015), [http://www.slate.com/blogs/future\\_tense/2015/06/23/devious\\_defecator\\_case\\_jury\\_awards\\_millions\\_over\\_illegal\\_dna\\_tests.html](http://www.slate.com/blogs/future_tense/2015/06/23/devious_defecator_case_jury_awards_millions_over_illegal_dna_tests.html) (last accessed Dec. 22, 2015).

<sup>147</sup> *GINA: Forensic Lab Exception to Rules prohibiting Acquisition of Genetic Information*, U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, (Jun. 6, 2012), [http://www.eeoc.gov/eeoc/foia/letters/2012/gina\\_forensic\\_lab\\_exception.html](http://www.eeoc.gov/eeoc/foia/letters/2012/gina_forensic_lab_exception.html) (last accessed Dec. 22, 2015).

<sup>148</sup> *Id.*

unreasonably restrictive. DNA cannot be used for investigatory purpose to resolve a workplace violation.

## **XI. CONCLUSION**

With only a short history behind it, GINA's core provisions of anti-discrimination and anti-retaliation provide welcome relief for employees concerned about preserving their livelihood in the face of a diagnosis of a genetic disease or disorder.

The the fringes, however, some of GINA's provisions potentially may be applied more broadly than its drafters originally anticipated. Employers who currently administer or require pre-employment medical exams are particularly cautioned about the need to affirmatively prevent collection of an employee's family medical history, whether or not the employer itself is performing those exams. Employers are further advised to conduct training regarding the confidentiality and recordkeeping required of supervisors upon gaining knowledge of an employee's or family member's health status. Meanwhile, questions remain as to of what type of acquisition of genetic material is permitted, what level of intent is required, and whether and to what extent wellness programs and forensic testing will be allowed.

With legislation and regulation currently pending and more EEOC decisions and court opinions being rendered every month, GINA's implications for the workplace have yet to fully be seen.