OOC BROWN BAG LUNCH SERIES
GENETIC INFORMATION NONDISCRIMINATION ACT
JULY 18, 2018

I. Introduction

The Genetic Information Nondiscrimination Act of 2008 (GINA), 42 U.S.C. § 2000ff *et seq*., prohibits discrimination by employers, employment agencies, and labor organizations against individuals on the basis of genetic information. Prior to the law's passage, some employers had implemented pre-employment genetic screening tests, and Congress found that it had "a compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance." 42 U.S.C. § 2000ff note, Pub. L. No. 110–233, 122 Stat. 881 (2008). Deeming the "patchwork" of state and federal laws protecting individuals from genetic discrimination to be "confusing and inadequate," Congress passed GINA "to fully 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." *Id*.

The Congressional Accountability Act of 1995 (CAA), 2 U.S.C. § 1301 *et seq*., applies certain federal labor and employment law statutes to all Legislative Branch employing offices and employees. The CAA predates GINA and therefore does not mention it, but GINA by its terms applies to covered employees (including applicants) and employing offices as defined in the CAA. 42 U.S.C. § 2000ff(2)(A)(iii), (B)(iii). GINA claims brought under the CAA are generally to be treated like Title VII discrimination claims brought under section 201(a)(1) of the CAA, 2 U.S.C. § 1311(a)(1). 42 U.S.C. § 2000ff-6(c)(1).

Among the provisions of the Congressional Accountability Act of 1995 Reform Act, S. 2952, 115th Cong. (as passed by Senate, May 24, 2018), is a proposed Section 301 that would state as follows: "The provisions of this Act that apply to a violation of section 201(a)(1) shall be considered to apply to a violation of title II of the Genetic Information Nondiscrimination Act of 2008 (42 U.S.C. 2000ff et seq.), consistent with section 207(c) of that Act (42 U.S.C. 18 2000ff–6(c))." If this language is included in the final legislation, it will not create any substantive changes to the rights and responsibilities of covered employees or employing offices; rather, it will make clear to anyone reading the CAA that GINA applies, and that claims brought for violations of GINA are treated in essentially the same manner as Title VII claims.

The Board of Directors of the Office of Compliance (OOC Board) has not yet had occasion to decide a case involving GINA. However, as with other statutes applied by the CAA, in interpreting the statute the OOC Board would look to persuasive case law, including but not limited to the cases discussed below, and the EEOC's regulations, which are found at 29 C.F.R. Part 1635.

II. What is "Genetic Information"?

The statute and regulations include definitions of "genetic information," "genetic services," and "genetic tests," but the courts have been somewhat inconsistent in their application of those definitions to individual cases.

1. Statutory Definitions

a) The statute defines "genetic information" as, with respect to an individual, "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. 42 U.S.C. § 2000ff(4)(A). Also included is "any request for, or receipt of, genetic services, or participation in clinical research which includes genetic services, by such individual or any family member of such individual." 42 U.S.C. § 2000ff(4)(B).

b) Specifically *excluded* from the definition of "genetic information" is "information about the sex or age of any individual." 42 U.S.C. § 2000ff(4)(C).

c) The term "genetic services" is defined as "(A) a genetic test; (B) genetic counseling (including obtaining, interpreting, or assessing genetic information); or (C) genetic education." 42 U.S.C. § 2000ff(6).

d) The term "genetic test" is defined as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes." 42 U.S.C. § 2000ff(7)(A). The term does not include "an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes." 42 U.S.C. § 2000ff(7)(B).

e) The statute distinguishes between "genetic information" and "medical information that is not genetic information," and provides that an employer "shall not be considered to be in violation of this chapter based on the use, acquisition, or disclosure of 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." 42 U.S.C. § 2000ff-9.[1]

2. EEOC Regulations

a) The EEOC regulations define "genetic information" in a similar manner to the statute, and expand that definition to include "[t]he genetic information of a fetus carried by an individual or by a pregnant woman who is a family member of the individual and the genetic information of any embryo legally held by the individual or family member using an assisted reproductive technology." 29 C.F.R. § 1635.3(c)(1)(v).

[1] For a good analysis of the gray area between "genetic information" (i.e., information about a disease that has not yet manifested) and "medical information that is not genetic information" (i.e., a disease, disorder, or medical condition that has already manifested), see Mark. A Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36(4) J. L. Med. & Ethics, 837-40 (2008).

b) As in the statute, the regulations exclude information about the individual's sex and age; the regulations further exclude "the sex or age of family members, or information about the race or ethnicity of the individual or family members that is not derived from a genetic test." 29 C.F.R. § 1635.3(c)(2).

c) The regulations provide a non-exhaustive list of tests that are considered "genetic tests" under GINA. Some examples include: tests for predisposition to breast cancer, nonpolyposis colon cancer, and Huntington's disease; carrier screenings for adults to determine risk of conditions such as cystic fibrosis or sickle cell anemia; evaluations used to determine the presence of genetic abnormalities in a fetus during pregnancy; newborn screening analysis that uses genetic information; ancestry genetic tests; paternity tests; and tests to determine predisposition for alcoholism or drug use. 29 C.F.R. § 1635.3(f)(2).

d) By contrast, some examples of tests that are *not* considered to be "genetic tests" under GINA include: medical examinations that test for the presence of a virus that is not composed of human DNA, RNA, chromosomes, proteins, or metabolites; tests for infectious disease that may be transmitted through food handling; complete blood counts, cholesterol tests, and liver-function tests; or tests for presence of alcohol or drug use. 29 C.F.R. § 1635.3(f)(3).

e) Under 29 C.F.R. § 1635.3(g), "Manifestation or manifested means, with respect to a disease, disorder, or pathological condition, that an individual has been or could reasonably be diagnosed with the disease, disorder, or pathological condition by a health care professional with appropriate training and expertise in the field of medicine involved. For purposes of this part, a disease, disorder, or pathological condition is not manifested if the diagnosis is based principally on genetic information."

3. Case Law

a) *Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC*, 102 F. Supp. 3d 1360 (N.D. Ga. 2015) – Genetic information includes information which does not inform about an individual's propensity for disease. Atlas requested cheek cell samples from certain employees as part of an investigation into an unknown employee who was relieving himself in a warehouse. The investigation involved comparing "genetic spacers" in the employees' DNA to the DNA in the sample at issue. However, this method could not determine an individual's propensity for a disease or disorder. Two of the tested employees brought this suit under GINA's prohibition on employers requesting, requiring, and disclosing genetic information. The court noted that a genetic test under GINA includes analyses of DNA and declined to limit the plain language of GINA to exclude DNA analyses which do not reveal an individual's propensity for disease. Even considering legislative purpose, the court noted examples from the legislative history which indicate that the reach of GINA is broader than Atlas contended. Moreover, the court noted that even the EEOC regulations do not limit the definition of "genetic test" as Atlas argued because the EEOC's list of genetic tests is not exhaustive and because the list itself includes tests which do not reveal a propensity for disease. Therefore, the DNA analysis in the instant case was a genetic test and Atlas's request for the samples was a violation of GINA. Notably, the court found that it was irrelevant to the unlawful request claim whether the samples were coerced or given voluntarily.

b) *Lewis v. Gov't of the Dist. of Columbia*, 161 F. Supp. 3d 15 (D.D.C. 2015) – A request for drug testing is not a request for genetic information. An employee protested her employer's request for a drug test as a condition of continued employment. The employee claimed that the employer terminated her for refusing to comply with a mandated drug test, which she alleged was an improper request under GINA. The court dismissed this claim because a drug test is not a genetic test and does not yield genetic information as defined by GINA. The court also noted that EEOC guidance explicitly excludes drug and alcohol testing from the definition of genetic information.

c) *Hoffman v. Family Dollar Stores, Inc.*, 99 F. Supp. 3d 631 (W.D.N.C. 2015) – Employee claimed that employer was aware of, and disclosed to other employees and customers, his diagnosis of HIV, kidney failure, and viral gastroenteritis. Pointing to EEOC guidelines, the court held that none of these medical issues constituted genetic information about a disease or disorder, specifically noting that an HIV test is not an example of a genetic test. "Given that an HIV test is not a genetic test, any information [employee] alleges [employer] disclosed about his HIV diagnosis or test… is not considered genetic information protected by GINA."

d) *Smith v. Donahoe*, 917 F. Supp. 2d 562 (E.D. Va. 2013) – USPS employee conducted independent genetic research and published a book detailing his research and conclusions on "how DNA really works." The employee advertised his book on the USPS bulletin board, but the advertisement was removed, and his supervisors told him that he was not allowed to continue posting this advertisement on the bulletin board. The employee brought a suit alleging, among other charges, a GINA violation. The court held that "Plaintiff's book and accompanying genetic and religious theory on DNA do not constitute 'genetic information' under GINA. As a result, Plaintiff has failed to state plausibly a claim for genetic information discrimination under GINA, and [his complaint] therefore must be dismissed."

e) *Bronsdon v. City of Naples*, No. 2:13-CV-00778, 2014 U.S. Dist. LEXIS 70502 (M.D. Fla. May 22, 2014) – Employee of the City of Naples Fire Department filed a GINA discrimination suit after he was denied workers' compensation benefits on the basis of his family medical history and genetic information. During his employment, the Department obtained medical information indicating that the employee had a strong family history of heart disease; that he suffered from hypertension, which was genetically related; and that he suffered from coronary artery disease related to his blood pressure, family history, and hyperlipidemia. The Department also obtained confidential medical information pertaining to the medical condition of his mother without consent. Prior to his GINA suit, he filed a claim for workers' compensation benefits, but was denied based upon his genetic information and family medical history. During those proceedings, the City of Naples disclosed to its attorney the employee's family medical history and genetic information, including his mother's medical information, and also referred to this information during trial and depositions. Further, after the suit, the employee was subject to repeated harassment (including a needle hidden in his fire jacket) and was eventually placed on administrative leave. The employee then filed suit under GINA alleging discrimination on the basis of genetic information. The department argued that "[p]laintiff cannot state a claim for discrimination under GINA because no decision was made based upon genetic information; rather, any alleged decision was based upon plaintiff's manifested conditions." The court rejected this argument at the pleading stage,

holding that this "bare assertion" was inapplicable because "discrimination based on family medical history is prohibited under GINA, even if the individual has a manifested condition."

f) *Connor-Goodgame v. Wells Fargo Bank*, No. 2:12-cv-03426-IPJ, 2013 WL 5428448 (N.D. Ala. Sept. 26, 2013) – A temporary employee with Wells Fargo claimed to suffer from anxiety and depression as a result of her mother's death from AIDS, of which she informed her supervisor. Upon suspecting that her supervisor informed co-workers about her mother's AIDS diagnosis and her disability, the employee met with him to complain about this disclosure. She was terminated three days later and brought this claim for retaliation under GINA. First, the court found that the employee's mother's AIDS diagnosis was not genetic information because, per EEOC guidance, GINA is concerned with individuals who may be discriminated against because they are at increased risk of acquiring a condition in the future. Here, there was no chance that the employee would acquire HIV in the future because of her mother's AIDS. Moreover, EEOC guidance does not qualify an HIV test as a genetic test. Therefore, information about her mother's AIDS diagnosis was not genetic information within the GINA framework. Second, the court rejected the employee's contention that an employer may be liable for disclosure of non-genetic information regarding a disease or disorder held by an employee's family member. This argument "would give more protection to an employee's family member's information than to the actual employee's information" and the court refused to "provide such an absurd result." Therefore, because the disclosure of non-genetic information about the employee's mother's AIDS status did not violate GINA, the employee could not show retaliation for opposing an act made unlawful by GINA.

g) *Bell v. PSS World Med., Inc.*, No. 3:12–cv–381–J–99MMH–JRK, 2012 WL 6761660 (M.D. Fla. Dec. 7, 2012) – Employee suffering from a hyperthyroidism condition claimed she was denied reasonable accommodation from her employer, and that her employer began releasing confidential information regarding her medical conditions to her coworkers and supervisors. The court dismissed her GINA claim because she "failed to provide any basis, factual or otherwise, for the Court to reasonably infer that her hyperthyroidism, the 'confidential information,' or the 'confidential medical conditions' related to genetic testing and/or genetic information" as defined in GINA. Essentially, the court held that the employee failed to describe any genetic information that was shared with the employer. Because the employee failed to show precisely which genetic information was discriminatorily used against her, she failed to properly allege a valid claim under GINA.

h) *Poore v. Peterbilt of Bristol, L.L.C.*, No. 1:11CV00088, 2012 WL 1118214 (W.D. Va. Apr. 4, 2012) – Employee who was terminated after disclosing his wife's multiple sclerosis diagnosis claimed genetic discrimination in violation of GINA. The court dismissed this claim, observing that mere diagnosis of a family member is not considered genetic information if it is not taken into account "'with respect to any other individual'" (quoting H.R. Rep. No. 110-28, pt. 2, at 27 (2007)). The court first reasoned that the wife's diagnosis had "no predictive value" regarding the employee's susceptibility to the disease. The court then found that there was no allegation that the employer used the multiple sclerosis diagnosis to "forecast the tendency of any other individual to contract multiple sclerosis." Therefore, the information was not genetic in nature and the termination did not constitute discrimination under GINA.

i) *Jacobs v. Donnelly Commc'ns*, No. 1:13-cv-980-WSD, 2013 WL 5436682 (N.D. Ga. Sept. 26, 2013) – Employee alleged that her employer discriminated against her in violation of GINA due to her allergies. The court observed that, even if the employee is correct that allergies are a genetic condition, genetic conditions do not qualify as genetic information and therefore are not covered under GINA. Therefore, the employee failed to state a claim under GINA.

j) *Robinson v. Dungarvin Nevada, LLC*, No. 2:16–cv–00902–JAD–PAL, 2018 WL 547225 (D. Nev. May 11, 2017) – Employee's claim of discrimination based on genetic information, specifically "being black," failed because "Race is protected under Title VII, not under GINA."

k) *Andres M. v. Brennan*, EEOC Decision No. 0120171135, 2017 WL 2241332 (May 11, 2017) – "Muscular frame" and "size" are not references to medical history or genetic information.

l) *Rochelle F. v. Brennan*, EEOC Decision No. 0120162813, 2018 WL 1392278 (Mar. 7, 2018) – Employee alleged a violation of Title II of GINA, and identified her genetic information as Attention Deficit Disorder (ADD). The Board found that because ADD is not genetic information, she had failed to state a valid claim under GINA.

III. Acquisition of Genetic Information

GINA at 42 U.S.C. § 2000ff-1(b) makes it unlawful, with certain exceptions, "for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee [.]" The EEOC regulations at 29 C.F.R. § 1635.8(a) provide that unlawful requests for genetic information under GINA include:

- Conducting an internet search on an individual in any way that is likely to result in a covered entity obtaining genetic information;
- Actively listening to third-party conversations, or searching an individual's personal effects for the purpose of obtaining genetic information; and
- 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.

Employers also have a duty to ensure that hired doctors do not request genetic information during medical exams. 29 C.F.R. § 1635.8(d).

However, where employees voluntarily disclose information, courts typically will not find GINA violations.

1. Claims of Improper Acquisition

a) *EEOC v. Grisham Farm Prods., Inc.*, 191 F. Supp. 3d 994 (W.D. Mo. 2016) – The EEOC brought an action alleging that the employer violated GINA by requiring job applicants to fill out a health history before they would be considered for a job. The health history required applicants to reveal whether they had "[c]onsulted a doctor, chiropractor, therapist or other health care provider within the past 24 months and to identify whether future… diagnostic testing… [had] been recommended or discussed" with their medical

provider. The Court held that these questions violated GINA because they required applicants who had preventatively consulted with a physician, or had been told by a physician to obtain diagnostic testing in light of their family history, to reveal such information to the employer.

b) *Duignan v. City of Chicago*, 275 F. Supp. 3d 933 (N.D. Ill. 2017) – After a psychotic episode, a city police detective was charged for misconduct by the Superintendent of Police. Although initially facing disciplinary action, the employee was found not guilty by the Police Board after testing positive for Huntington's disease, which in part is characterized by progressively worsening psychiatric symptoms. After this episode, the employee underwent a psychological evaluation as requested by the department. The examination resulted in the conclusion that she was "unfit for duty as a police detective… based upon the progressive course of Huntington's disease and the lack of an adequate departmental system to continuously monitor medication compliance and the [employee's] psychological state." After the Superintendent filed additional charges of misconduct against her, the employee filed suit, alleging, among other charges, that the employer wrongfully requested her genetic information and wrongfully discriminated against her on the basis of her genetic information. The court dismissed the employee's GINA claims because her allegations "[did] not plausibly suggest that [the employer] requested her genetic information." Although the employee argued that it should be *inferred* that her employer requested her genetic information from the psychologist's finding she was unfit for duty in part based on "the progressive course of Huntington's disease," the court found that because the employee had already testified before the Board about her diagnosis of Huntington's disease, she had previously and voluntarily disclosed this information; "the fact that the psychologist considered [her] diagnosis… does not, without more, suggest that defendant unlawfully requested plaintiff's genetic information." Further, because the employee alleged a violation of the ADA on the basis that her psychosis "was organic in nature and a clinical manifestation of Huntington's disease," she "pled herself out of any claim that defendant took an adverse action against her based on her genetic information, as opposed to on her actual diagnosis of Huntington's disease, which is the substance of the discrimination claim she asserts under the ADA."

c) *Higgins v. Union Pac. R.R. Co.*, 303 F. Supp. 3d 945 (D. Neb. 2018), *appeal docketed*, No. 18-1902 (8th Cir. Apr. 27, 2018) – Employer requested employee's "entire medical chart" in relation to employee's ankle injury. However, the medical provider's representative testified that the company did not typically send employees' entire charts, and there was no evidence that the plaintiff's entire chart was sent in this case. Because the employee could not establish that his employer actually received his entire medical chart, he failed to show that his employer received any genetic information or took any injurious action based on genetic information.

2. Inadvertent Acquisition

One exception to the prohibition against the acquisition of genetic information is "where an employer inadvertently requests or requires family medical history of the employee or family member of the employee[.]" 42 U.S.C. § 2000ff-1(b)(1). However, the EEOC guidelines interpret the meaning of "inadvertently" narrowly. Therefore, when requesting an employee's medical history, employers should specifically include language notifying the healthcare

provider to exclude genetic information (see 29 C.F.R. § 1635.8(b)(1)(i)(B) for specific wording); otherwise, the receipt of genetic information in response to the request will not be considered "inadvertent," unless the employer can show that it did not reasonably expect to receive genetic information (e.g., where the employer's request for medical information is specifically targeted, but the healthcare provider sends a broad response that includes genetic information).

a) *Jackson v. Regal Beloit Am., Inc.*, No. 16-134-DLB-CJS, 2018 WL 3078760 (E.D. Ky. June 21, 2018) – The court found that the employer unlawfully requested Jackson's genetic information. Although EEOC regulations provide that an employer does not violate GINA "based on the use, acquisition, or disclosure of *medical information that is not genetic information* about a manifested disease, disorder, or pathological condition of the employee, even if the disease, disorder or pathological condition has or may have a genetic basis or component," 29 C.F.R. § 1635.12 (emphasis added), because the medical records included requests for protected "genetic information" in the form of the employee's family history, the employer made an unlawful request for genetic information. The court also found that, under GINA's plain language, employers have an affirmative duty to ensure that hired doctors do not violate GINA during the course of medical examinations requested by the employer. Further, the request was not inadvertent. EEOC regulations provide that if an employer acquires genetic information in response to a lawful request for medical information, the acquisition of such genetic information is generally not considered inadvertent unless the employer directs the provider not to provide genetic information. 29 C.F.R. § 1635.8(b)(1)(i)(A). Even despite the employer's failure to provide such direction, the employer failed to prove that "its request for medical information was not likely to result in a covered entity obtaining genetic information."

b) *Maxwell v. Verde Valley Ambulance Co.*, No. CV-13-08044-PCT-BSB, 2014 WL 4470512 (D. Ariz. Sept. 11, 2014) – Prior to his employment with VVAC, Maxwell suffered a leg injury that left him with a drop foot, limp, and frequent pain. VVAC was unaware of these conditions until it decided to terminate Maxwell for using company computers to plan a medical marijuana business. Upon becoming aware of Maxwell's condition, VVAC decided to send Maxwell to a physician prior to proceeding with the termination proceedings, to determine whether he was disabled. At the urgent care facility Maxwell was sent to, he filled out a form that requested family medical history, and disclosed that his grandfather had cancer. VVAC received this family history even though it had solicited and expected only a fitness-to-work letter. In addition to his ADA claims, Maxwell brought a GINA claim for unlawful request for medical information. VVAC moved for summary judgment, arguing that the receipt of the family history was inadvertent and that the urgent care was not an employee or agent of VVAC. The court, observing that acquisition is not inadvertent unless the employer directed the healthcare provider not to provide genetic information, found that VVAC did not meet the summary judgment standard in proving that the request was inadvertent. The court likewise observed that an employer's agent is included in GINA's definition of "employer," and that VVAC failed to show that the urgent care facility was not its agent.

3. Wellness Programs

Another exception encompasses medical information requests that are part of a health or wellness service offered by the employer, so long as the employee provides valid written authorization, and individually identifying information is not provided to the employer. 42 U.S.C. § 2000ff-1(b)(2)(A). Employer wellness programs offer incentives, such as insurance premium cost-sharing, when an employee meets defined health outcomes or based on an employee's health status. Such programs aim to promote employee health and productivity and reduce health-related costs. Examples may include programs focused on smoking cessation, weight loss, or preventive health screenings, among others.

EEOC regulations require such wellness programs to be reasonably designed to promote health or prevent disease, not overly burdensome, not a subterfuge for violating GINA, and not highly suspect in their methods. 29 C.F.R. § 1635.8(b)(2)(i)(A). The regulations prohibit employers from inducing employees to provide genetic information, but permit inducements offered as incentives for filling out health risk assessments or participating in wellness programs, provided certain conditions are satisfied. 29 C.F.R. § 1635.8(b)(2)(ii)-(vii).

a) *Fuentes v. City of San Antonio Fire Dep't*, 240 F. Supp. 3d 634 (W.D. Tex. 2017) – The wellness program at issue in this case involved a physical examination including: obtaining vital signs; obtaining body composition including body weight, fat percentage, and BMI; obtaining vision, hearing, and spirometry assessments; drawing blood for complete blood count, metabolism tests, cholesterol tests, Hepatitis C, and HIV; urinalysis; a chest x-ray; and a stress electrocardiogram. The employee refused to participate in the program, and was placed on administrative detail, which he alleged was a GINA violation. He subsequently agreed to submit to a physical exam by his own physician, but refused to provide the results to the Department, and was again placed on administrative detail, which he again claimed was a GINA violation. The court granted summary judgment in favor of the Department, holding that "GINA only applies to genetic information, not 'personal health information,' and there is no evidence that plaintiff was required to submit to genetic testing or to release family medical history in violation of GINA." Moreover, the court found "no evidence that any of these tests—including the blood tests—involve an analysis of human DNA, RNA, chromosomes, proteins, metabolites, genotypes, mutations, or chromosomal changes." Finally, there was no evidence that Fuentes was required to release genetic information or family medical history, or that he actually did so. "Thus, there is no evidence that any individually identifiable information was released to anyone other than the licensed health care professionals or disclosed in any manner other than aggregate terms allowed by GINA. Ultimately, because there is no evidence that any of the information collected by the program was genetic information, there is no evidence that GINA is even implicated here."

b) *Lee v. City of Moraine Fire Dept.* No. 3:13–cv–222, 2015 WL 914440 (S.D. Ohio Mar. 3, 2015) – The Fire Department's health and wellness program required firefighters to fill out a questionnaire that included questions about family history of heart disease and prostate cancer. The plaintiff firefighter not only refused to participate in the wellness program but also explained repeatedly to his supervisors that he believed the questions about family history were illegal. He was placed on administrative leave and eventually fired for insubordination, and subsequently filed a lawsuit alleging, among

other things, violations of GINA related to the requests for family history and retaliation for opposing those violations. The court agreed with the plaintiff on his unlawful request claim, holding that the family history questions violated GINA. Although the doctor, not the employer, was the entity asking the questions, GINA defines "employer" as a person employing a sufficient number of employees, and "any agent of such person." Further, the wellness program exception only applies when "the employee provides prior, knowing, voluntary and written authorization." 42 U.S.C. § 2000ff-1(b)(2)(B). Under EEOC regulations, written authorization forms must (1) be written so that the individual from whom the genetic information is being obtained is reasonably likely to understand it; (2) describe the type of genetic information that will be obtained and the general purposes for which it will be used; and (3) describe the restrictions on disclosure of genetic information. 29 C.F.R. § 1635.8(b)(2)(i)(C). Because the city's agent requested genetic information and failed to include the required written authorization form provisions, the city violated GINA. However, the court held in favor of the Department on the retaliation claim, explaining that there was no genuine issue of fact that the plaintiff "was terminated for insubordination, which in the context of a duty-bound organization such as a fire department, can justify a termination for insubordinately standing on one's legal and even constitutional rights."

c) *AARP v. EEOC*, 267 F. Supp. 3d 14 (D.D.C. 2017) – The AARP challenged two EEOC regulations under the Administrative Procedures Act, one concerning the ADA and the other concerning GINA. The GINA rule permitted employers to offer incentives of up to 30% of the cost of self-only coverage for disclosure of information, pursuant to a wellness program, about a spouse's manifestation of disease or disorder, which constitutes genetic information under GINA. The AARP argued that the 30% incentive was inconsistent with the "voluntary" requirement of GINA, because employees who could not afford to pay a 30% increase in premiums would be forced to disclose their protected information when they otherwise would choose not to do so. The court applied a *Chevron* analysis to the EEOC's interpretation of the term "voluntary," holding first that the term as used in GINA is ambiguous, and second that the decision to permit employers to provide wellness program incentives of up to 30% was "neither reasonable nor supported by the administrative record." The EEOC failed to explain why incentives of over 30% would be coercive, rendering the disclosure of genetic information involuntary, but incentives of 30% or lower would not. The court granted the AARP's motion for summary judgment, and initially remanded to the EEOC for reconsideration; several months later, the court vacated the challenged portions of the EEOC's rules, although it stayed the effective date of the vacatur order until January 1, 2019. *See* 292 F. Supp. 3d 238 (D.D.C. 2017).

4. Other Exceptions

Under the statute, it is also permissible for an employer to:

- Require family medical history to comply with FMLA, 42 U.S.C. § 2000ff-1(b)(3);
- Gain information through publicly available documents, 42 U.S.C. § 2000ff-1(b)(4);
- Request information to monitor effects of toxic substances as part of a hazardous workplace environment evaluation, 42 U.S.C. § 2000ff-1(b)(5); or
- Request information for certain specified law enforcement purposes, i.e., as a forensic laboratory or for purposes of human remains identification, 42 U.S.C. § 2000ff-1(b)(6).

a) *Lowe v. Atlas Logistics Grp. Retail Servs. (Atlanta), LLC*, 102 F. Supp. 3d 1360 (N.D. Ga. 2015) – GINA allows employers to collect genetic information for law enforcement purposes only for use in quality control and detecting sample contamination at crime scenes. This exception applies to employers such as law enforcement agencies and forensic laboratories and helps to "eliminat[e] DNA profiles which belong to an employee instead of a true perpetrator."

b) *Burns v. Dep't of Pub. Safety*, 973 F. Supp. 2d 141 (D. Conn. 2013) – Although this claim was brought under a state genetic non-discrimination statute, the court's comparison to GINA is instructive. The employer, a state law enforcement agency, required employees to submit DNA samples for comparison at crime scenes in order to identify where the crime scene had been contaminated by employees. The agency planned to limit assignments to crime scenes to employees who had submitted DNA samples. Although the agency asserted that DNA collection in this context was permissible under GINA's exception for law enforcement quality control and contamination detection, the court found that Connecticut's genetic non-discrimination statute did not provide an analogous exception.

c) *Hawkins v. Jam. Hosp. Med. Ctr. Diagnostic & Treatment Ctr. Corp*, No. 16 CV 4265, 2018 WL 3134415 (E.D.N.Y. Feb. 26, 2018) – Terminated employee filed a charge with the EEOC alleging, among other things, that his employing hospital violated GINA based on the fact that during the hiring process, job applicants were required to provide genetic and medical information about themselves and their family members. The EEOC issued a decision on the charge, determining that based on the genetic and family medical information the hospital required applicants to provide in the form, there was reasonable cause to believe that the hospital violated GINA. The EEOC issued a right to sue letter to Hawkins, and he filed a putative class action against his employer on behalf of himself and fellow employees present at the hospital since the passage of GINA. The hospital argued that the tests were conducted as part of a genetic monitoring program, because the employees were "exposed to carcinogens and blood borne pathogens" through their jobs in the hospital, and therefore fell under the exemption for genetic monitoring programs. The court rejected this argument because the employer failed to present evidence that any of the proposed class members actually encountered the carcinogens and pathogens, and failed to cite a single OSHA regulation entitling hospitals to obtain family information, as opposed to personal medical information relevant to such carcinogen exposure.

d) Occupational safety and health regulations may require employers to monitor employee health in order to target worksites for increased safety and health precautions. Medical surveillance programs, such as those required by the Occupational Safety and Health Act (OSHAct), monitor employees over time in order to detect early signs of conditions that may be related to hazardous substance exposure in the workplace. Genetic monitoring assesses changes in an individual's genetic material over time due to workplace exposure to hazardous substances. Employers may retain a medical professional to monitor and retain records of exposure levels in individuals, or may refer employees to clinics that collect and retain the information. For more information about medical surveillance under the OSHAct, see https://www.osha.gov/SLTC/medicalsurveillance/.

e) Under the EEOC regulations, GINA generally is not violated when genetic information is acquired from "documents that are commercially and publicly available for review or purchase," which includes newspapers, magazines, periodicals, or books, or electronic media such as television, movies, or the internet. 29 C.F.R. § 1635.8(b)(4). However, there are many exceptions to this principle. For example, GINA may be violated if an employer acquires genetic information from "medical databases, court records, or research databases available to scientists on a restricted basis," *id*. at § 1635.8(b)(4)(i); "through sources with limited access, such as social networking sites and other media sources which require permission to access from a specific individual or where access is conditioned on membership in a particular group, unless the covered entity can show that access is routinely granted to all who request it," *id*. at § 1635.8(b)(4)(ii); or in certain circumstances where the employer accesses the document "with the intent of obtaining genetic information" or where the employer is "likely to acquire genetic information by accessing those sources, such as Web sites and on-line discussion groups that focus on issues such as genetic testing of individuals and genetic discrimination," *id*. at § 1635.8(b)(4)(iii)-(iv).

IV. Confidentiality

If employers do obtain employees' genetic information, GINA requires them to treat that information as confidential. The genetic 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." 42 U.S.C. § 2000ff-5(a).

The statute carves out several exceptions to the confidentiality rules. 42 U.S.C. § 2000ff-5(b) provides that an employer shall not disclose the genetic information except:

> (1) to the employee or the employee's family member (if the family member received the genetic services) at the employee's written request;
>
> (2) to an occupational health researcher if the research is conducted in compliance with federal regulations;
>
> (3) in response to a court order, as long as the employer only discloses such information expressly authorized in the order and, if the court order was secured without the knowledge of the employee, the employer must inform the employee of the order and any genetic information disclosed pursuant to the order;
>
> (4) to government officials who are investigating compliance with GINA if the information is relevant to the investigation;
>
> (5) when disclosure is made in connection to FMLA or state medical leave laws;
>
> (6) to a federal, state, or local public health agency concerning a contagious disease that presents an imminent public hazard.

V. Discrimination Claims

GINA at 42 U.S.C. § 2000ff-1(a) provides that it is unlawful for an employer:

> (1) to fail or refuse to hire, or to discharge, any employee, or otherwise to discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information with respect to the employee; or
>
> (2) to limit, segregate, or classify the employees of the employer in any way that would deprive or tend to deprive any employee of employment opportunities or otherwise adversely affect the status of the employee as an employee, because of genetic information with respect to the employee.

It is also impermissible for employers to discriminate against or segregate employees based on genetic information when it comes to apprenticeships, training, or retraining. 42 U.S.C. § 2000ff-4.

To succeed on a claim for genetic discrimination under GINA, it is not enough for a plaintiff to allege that the employer *had* genetic information – he or she must also show that the employer *used* the genetic information when taking the adverse action. *See Punt v. Kelly Servs.*, 862 F.3d 1040 (10th Cir. 2017); *Allen v. Verizon Wireless*, No. 3:12-cv-482, 2013 WL 2467923 (D. Conn. June 6, 2013).

Because this is a relatively new statute, the body of case law applying it is still fairly small, and there do not appear to be any universally-applied elements or frameworks for analyzing GINA discrimination claims. Some courts have used a Title VII burden-shifting analysis, while others have looked solely at whether the plaintiff could show that the adverse employment action was motivated by genetic information.

a) *Jackson v. Regal Beloit Am., Inc.*, No. 16-134-DLB-CJS, 2018 WL 3078760 (E.D. Ky. June 21, 2018) – An employee who operated powered industrial equipment was diagnosed with colon cancer, underwent surgery, returned to work, and resumed her position without any performance issues. A few months after her return, however, her employer requested that she undergo a medical screening during which the screening doctor requested her prior medical records. The employee repeatedly refused. The employer, justifying its request for medical records as "needed to understand her history so they could authorize her to be safe to operate [powered industrial equipment]," terminated the employee. She filed a number of claims, including allegations of discrimination, unlawful request, and retaliation under GINA. First, for the claim of discrimination based on genetic information, the court adopted a Title VII discrimination burden-shifting analysis. Although the elements for a prima facie case of GINA discrimination are "unclear," the court explained that "[g]iven GINA's heavy reliance on Title VII… a plaintiff will likely have to prove that she is entitled to protection under the statute, that she was qualified for her position, that she suffered an adverse employment action, and that the employer favored applicants or employees in a way that evinces discrimination on the basis of genetic information." In this case, the employee's discrimination claim failed because the employee refused to provide her genetic

information to her employer; therefore, discrimination based on genetic information could not have occurred.

b) *Punt v. Kelly Servs.*, 862 F.3d 1040 (10th Cir. 2017) – An employee cannot show genetic discrimination absent evidence that an employer's knowledge of genetic information contributed to the adverse action. Punt, a temporary employee, informed her employer of her breast cancer diagnosis, her need to be absent from work to undergo treatment, and her family's history of breast cancer diagnoses. After numerous unannounced absences, the employer terminated Punt. Punt claimed that this termination was discrimination based on genetic information because a jury *could* find that her employer had made assumptions about her treatment needs based on the "genetic information" of having multiple family members with breast cancer diagnoses. The court rejected this argument, noting that it "would require rank speculation, without any supporting evidence, regarding Defendants' assumptions about the role of a family history of breast cancer on a breast-cancer patient's treatment and recovery." Moreover, even if the employee had presented supporting evidence, she failed to present evidence or argument that the proffered reason for the termination was pretextual.

c) *Tovar v. United Airlines Inc.*, 985 F. Supp. 2d 862 (N.D. Ill. 2013) – Terminated employee alleged that his employer discriminated against him based on genetic information, specifically his disclosure to his supervisor that his mother had diabetes. However, he failed to present any evidence that his supervisor's knowledge of his mother's diabetes was used in any employment decisions. He was given a leave of absence to visit his mother, and was not denied any of the leave benefits he requested. Moreover, there was no evidence that the individuals who terminated him were aware that his mother had diabetes when they terminated him. Instead, the evidence showed that the employee was terminated because of his threatening and intimidating behavior towards coworkers.

d) *Jones v. Foxx,* No. 16-2207-CM, 2018 WL 705665 (D. Kan. Feb. 5, 2018) – Employee alleged various forms of discrimination based on genetic information, specifically her sickle cell anemia. Although the employee had previously told her employer that her oldest son died of sickle cell anemia, she never mentioned her own sickle cell anemia during the period when the alleged adverse actions occurred, which began approximately 10 years later. Her GINA claims failed because "[t]he uncontroverted facts" showed that the employee's supervisor was unaware that she had sickle cell or any other disability, and did not talk with her about it or otherwise mention it. "No reasonable factfinder could conclude that [the supervisor] was motivated by plaintiff's sickle cell anemia when he made [the challenged] employment decisions[.]"

e) *Gibson v. Wayfair, Inc.*, No. 4:17-2059, 2018 WL 3140242 (S.D. Tex. June 27, 2018) – Employee alleged that her termination was the result of discrimination based on genetic information regarding her mother's unspecified mental illness. The evidence showed that the only time the employee had mentioned her mother's mental illness to her employer was when she requested permission to go home during her lunch break to check on her minor daughter, explaining to her supervisor that the employee's mother had a mental illness and therefore couldn't take care of the child. The court rejected her GINA discrimination claim, noting that the employer had used the very limited general information Plaintiff disclosed about her mother's condition only in connection with

granting Plaintiff's request to go home during her lunch break to check on her daughter. "Evidence that Plaintiff described her mother generally as 'mentally ill' has no predictive value with respect to Plaintiff's genetic propensity to acquire a specific mental illness, and there is no evidence that Wayfair viewed it as such."

f) *Carroll v. Comprehensive Women's Health Servs.*, No. 3:16CV1509, 2017 WL 4284386 (M.D. Pa. Sept. 27, 2017) – Employee alleged discrimination based on genetic information after she requested leave from her employer to undergo genetic testing to see if she had "a cancer gene." She was fired on February 6, 2013, and received her genetic testing results on February 19, 2013. The court agreed with the employer's argument that she failed to establish her claim "simply because of the timeline[.]" The court concluded that employee "could not have been fired because of information from her genetic tests because the results of those tests were not yet known at the time she was fired."

g) *Allen v. Verizon Wireless*, No. 3:12-cv-482, 2013 WL 2467923 (D. Conn. June 6, 2013) – The plaintiff was a customer service representative and business support coordinator for Verizon. She made an FMLA request in order to care for her mother, and included her mother's confidential medical information. She later requested FMLA and short-term disability (STD) leave due to allergies, fatigue, and sleep testing. In processing this claim, Metlife (which handled these types of claims for Verizon) contacted the employee's mother's health care provider. The request for FMLA leave was denied, and the employee received a "final written warning" and memorandum on how to manage her time off. She later requested additional FMLA and STD leave, and Metlife denied those requests as well. After the employee's prolonged absence from work, she was terminated for job abandonment. She alleged that Verizon violated GINA by denying her STD request due to her family's medical history. The court dismissed the GINA claim, noting that "evidence of a family member's disease diagnosis is only considered 'genetic information' if used to determine the likelihood of disease in another individual." The court also cast doubt on whether the employee had actually alleged that her mother's medical information was used as genetic information, given the employee's claim that she herself was reported as suffering from her mother's condition.

h) *Dong F. v. Jewell*, EEOC Decision No. 0120140109, 2016 WL 3361301 (June 3, 2016) – Employee with color vision deficiency presented a written statement from his optometrist disclosing that 6% of males have similar vision deficiencies "congenitally." When his employer denied a medical waiver for his disability, and subsequently terminated him, he filed an EEOC complaint alleging his employer discriminated against him in violation of GINA. The Board held that the employee was "not covered by GINA since an individual who has a current impairment is not protected from discrimination on the basis of that impairment by GINA, even if the condition has a genetic basis, but rather would be protected by the Rehabilitation Act."

i) *Sid E. v. Shulkin*, EEOC Decision No. 0120150867, 2017 WL 5564409 (Nov. 8, 2017) – Employee alleged that he was discriminated against after he informed his employer that there was a genetic marker related to his iron intake issue. When asked whether he believed that his employer's actions were motivated by unlawful considerations of his genetic information, he did not answer affirmatively. The Board found that the employee did not meet his burden of proof to show that such information played a role in any of the incidents at issue.

VI. Retaliation Claims

GINA contains an anti-retaliation provision, which provides that "[n]o person shall discriminate against any 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." 42 U.S.C. § 2000ff-6(f). The EEOC regulations echo this language at 29 C.F.R. § 1635.7. Additionally, section 207 of the CAA, 2 U.S.C. § 1317, protects employees from intimidation, reprisal, or discrimination "because the covered employee has opposed any practice made unlawful by this chapter, or because the covered employee has initiated proceedings, made a charge, or testified, assisted, or participated in any manner in a hearing or other proceeding under this chapter," which would include opposing practices that violate GINA or participating in a proceeding pursuant to allegations of GINA violations.

Courts analyzing GINA retaliation claims have typically applied the *McDonnell Douglas* burden-shifting framework, which originated in the Title VII context. *See McDonnell Douglas Corp. v. Green*, 411 U.S. 792 (1973). The framework requires a plaintiff to first make out a prima facie case by showing that (1) he engaged in protected activity by opposing a practice made unlawful by GINA, (2) he suffered an adverse employment action, and (3) a causal link existed between the protected activity and the adverse action. The burden then shifts to the employer to articulate a legitimate, non-retaliatory reason for the adverse employment action. The employee then has the opportunity to demonstrate that the employer's reason is actually a pretext for retaliation.

a) *Ortiz v. City of San Antonio Fire Dep't*, 806 F.3d 822 (5th Cir. 2015) – A San Antonio Fire Department employee brought claims for discrimination and retaliation in violation of GINA in response to a mandatory wellness program. The program required all employees to submit a medical history; physical examination; blood and urine test results; tests results for vision, hearing, and lung capacity; chest x-rays; and a stress test. Employees failing to do so or who were not certified fit were placed on "alternate duty." First, the court found that the information requested by SAFD for the wellness program was not actually genetic information and that Ortiz did not present evidence of discrimination based on genetic information. Therefore, the court dismissed Ortiz's discrimination claim because requesting and using non-genetic medical information does not violate GINA. Second, the court used a Title VII burden-shifting framework to analyze the GINA retaliation claim. The court dismissed Ortiz's retaliation claim because (1) there was no causation because he filed his EEOC complaint *after* the adverse action of being placed on alternate duty, (2) refusal to comply was not a protected activity because Ortiz did not specifically refer to a GINA-protected activity when he refused to comply, and (3) placing Ortiz on administrative duty was a legitimate response to his refusal to comply with a program designed to ensure that firefighters could perform their jobs safely and effectively.

b) *Jackson v. Regal Beloit Am., Inc.*, No. 16-134-DLB-CJS, 2018 WL 3078760 (E.D. Ky. June 21, 2018) – The court, "assuming" that the *Ortiz* Title VII retaliation burden-shifting framework was appropriate, found that the employee presented a sufficient prima facie case that her opposition to the screening doctor's medical records request caused her to be terminated, and the employer failed to proffer a legitimate, nondiscriminatory reason for the adverse employment action. Notably, the court observed that the employee's

refusal to submit medical records was not a legitimate, non-discriminatory reason for termination.

c) *Fuentes v. City of San Antonio Fire Dep't*, 240 F. Supp. 3d 634 (W.D. Tex. 2017) – Firefighter assigned to punitive administrative duties alleged his employer retaliated against him in violation of GINA after he refused to participate in his employer's wellness program. The program required all uniformed personnel to undergo a physical exam and a stress electrocardiogram. There was no evidence that any of the wellness program tests were genetic, as they did not involve analysis of human DNA, RNA, chromosomes, proteins, metabolites, genotypes, mutations, or chromosomal changes, and there was no evidence that the employee was required to submit family medical history under the program. The court found that the employee's refusal to participate in the program was not opposition activity because there was no evidence that the program included any practice made unlawful under GINA. Further, he did not engage in protected activity when he raised objections to his employer about "the dissemination of [his] personal medical History and that of [his] family [as] an invasion of [his] privacy" because he did not "specifically [refer] to a discriminatory practice under GINA."

d) *Connor-Goodgame v. Wells Fargo Bank*, No. 2:12-cv-03426-IPJ, 2013 WL 5428448 (N.D. Ala. Sept. 26, 2013) – A temporary employee was terminated three days after complaining about her supervisor's suspected disclosure of her mother's AIDS diagnosis, and alleged retaliation under GINA. The court held that because her mother's AIDS diagnosis was not "genetic information" under GINA, such a disclosure was not prohibited. Therefore, the employee had not opposed a practice made unlawful by GINA, and her retaliation claim failed.