

To: New Jersey Law Revision Commission
From: Vito J. Petitti
Re: Uniform Protection of Genetic Information in Employment Act (UPGIEA)
Date: May 12, 2014

MEMORANDUM

This Memorandum is intended to update the Commission regarding the Uniform Protection of Genetic Information in Employment Act (UPGIEA), approved by the Uniform Law Commission (ULC) in July 2010 for enactment in all the States. Preliminary research and drafting for this potential project was conducted by Rutgers School of Law – Camden pro bono student, Amanda Follett.

Executive Summary

Staff requests the Commission’s authorization to conduct further research and analysis, and to engage in outreach for comment on this project, with a view to the possible recommendation of all or part of the UPGIEA for adoption in New Jersey.

A majority of states, including New Jersey, have enacted their own statutes regulating how employers collect, use, retain, or disclose employees’ genetic information.¹ In 1996, New Jersey enacted one of the most comprehensive laws protecting genetic information, known as the Genetic Privacy Act (“GPA”). In 2008, Congress passed the Genetic Information Nondiscrimination Act (“GINA”) in response to the explosion in the science of genetics and in recognition of the potential for discrimination based on genetic information.² The UPGIEA, released in 2010 and not yet adopted in any state, attempts to comprehensively regulate “acquisition, use, retention, and disclosure of genetic information in the context of employment” and “allows individuals to control the privacy of their genetic information, preventing the misuse of that information.”³

Although New Jersey already has legislation in place, the Commission may wish to consider recommending all or part of the UPGIEA for enactment in light of the importance of promoting genetic testing and research, GINA’s known limitations, and potential confusion regarding the interaction between GINA and state laws, as discussed below.

Existing New Jersey Law

New Jersey’s Genetic Privacy Act⁴ (“GPA”) is described as “[o]ne of the most comprehensive laws protecting genetic information” to be passed by any state.⁵ The GPA treats

¹ Uniform Protection of Genetic Information in Employment Act (2010)

² Genetic Information Nondiscrimination Act, Pub. L. No. 110-233 (2010)

³ Acts: Protection of Genetic Information in Employment Act, Description, Uniform Law Commission (2013), <http://www.uniformlaws.org> (last visited 5/7/2014)

⁴ *N.J.S.* 10:5-5, *N.J.S.* 10:5-12, *N.J.S.* 10:5-43 to 49, *N.J.S.* 17:48-6.18, *N.J.S.* 17:48A-6.11, *N.J.S.* 17:48E-15.2, *N.J.S.* 17B:26-3.2, *N.J.S.* 17B:27-36.2, *N.J.S.* 17B:30-12, *N.J.S.* 26:2J-15.1.

genetic information as a person's private property.⁶ Section 10:5-45 of the GPA provides that "[n]o person shall obtain genetic information from an individual, or from an individual's DNA sample, without first obtaining informed consent from the individual or the individual's representative."⁷ Correspondingly, Section 10:5-46 contains exceptions to GPA.⁸ For example, the GPA does not fully apply in criminal investigations or paternity suits.⁹ Section 10:5-47 regulates disclosure of genetic information,¹⁰ and Section 10:5-48 governs notice requirements for persons to be tested and the process for obtaining informed consent.¹¹ Subsection 10:5-48(b) provides, with certain exceptions, that the "Commissioner of Health and Senior Services, in consultation with the Commissioner of Banking and Insurance, shall promulgate regulations...governing procedures for obtaining informed written consent..." Subsection 10:5-48(c) provides, however, that "[t]he provisions of this section shall not apply to newborn screening requirements established by State or federal law." Finally, Section 10:5-49 governs penalties for anyone found in violation of the GPA¹² and provides for both monetary fines and terms of imprisonment.

Similar to GINA, the federal law in this area, New Jersey's GPA prohibits employers from discriminating against individuals based on their genetic information.¹³ Under the GPA, employers cannot discriminate against a prospective or future employee because of her genetic information, because she declines to take a genetic test, or because she fails to "make available the results of a genetic test."¹⁴ New Jersey law also prohibits "unfair discrimination against an individual in the application of the results of a genetic test or genetic information in the issuance, withholding, extension or renewal of a policy of life insurance."¹⁵ If an insurer plans to use genetic test results, it must "notify the individual who is the subject of the genetic test that such a test [will] be required and [must] obtain the individual's written informed consent for the test prior to the administration of the test."¹⁶ The insurer must also provide the results of the test to a "physician or other health care professional designated by the individual" and the individual can indicate in writing if she wishes "to be informed of the results of the test."¹⁷

In New Jersey, there is a private right of action for victims of employment discrimination and a plaintiff may initiate suit by filing in Superior Court.¹⁸

⁵ GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, 102 (2009)

⁶ *Id.* at 102-03.

⁷ *N.J.S.* 10:5-45.

⁸ *N.J.S.* 10:5-46.

⁹ See *Id.*

¹⁰ *N.J.S.* 10:5-47.

¹¹ *N.J.S.* 10:5-48.

¹² *N.J.S.* 10:5-49.

¹³ *New Jersey Passes Genetic Privacy Bill*, BMJ 1996;313:71.1, <http://www.bmj.com> (last visited 5/8/2014).

¹⁴ *Id.*, *N.J.S.* 17B:30-12.

¹⁵ GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, at 103 (2009) (quoting *N.J.S.* 17B:30-12(f)).

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ See *N.J.S.* 10:5-13.

Preliminary research indicates that there is no legislation presently being considered in New Jersey that focuses on this area of the law.

Other States

Although at least 37 states have enacted legislation concerning employment-related collection, use, retention, and disclosure of genetic information, no states have enacted any versions of the UPGIEA as of the date of this Memorandum.¹⁹ New Mexico is the only state to introduce a bill enacting the UPGIEA,²⁰ but the bill – SB 445 – died in committee.²¹

According to New Mexico Senator Cisco McSorley's Fiscal Impact Report, SB 445 significantly differs from the UPGIEA in several ways, including conflicting definitions of "employee," the Act's inclusion of employer agents in its "employer" definition, and the guidance contained in New Mexico's bill regarding inadvertent acquisition of genetic information.²²

Upon review of SB 445, the New Mexico Attorney General's Office articulated its concern that "the numerous exceptions outlined in the proposed legislation, including the allowances for inadvertent requests, requirement or acquisition of genetic information through genetic testing provides many loopholes and opportunities to avoid prosecution."²³ Moreover, New Mexico's Administrative Office of the Courts ("AOC") identified issues with certain definitions contained in the Act.

Why the Uniform Law Commission believes UPGIEA is Necessary

The ULC believes there is a need for states to uniformly regulate the disclosure and use of genetic information in the workplace, especially considering GINA's employment provisions do not preempt state legislation that provides equal or greater protection to individuals.²⁴

The ULC emphasizes that the UPGIEA must be passed (1) to encourage individuals to take genetic tests, (2) to clear up confusion regarding whether GINA preempts existing state laws, and (3) to promote uniformity among states.²⁵ While scientific developments in the field of genetics hold many promises for the future, individuals will be unwilling to take genetic tests unless they are confident that they can control the privacy of their genetic information and that their genetic information will not be used to harm them in the workplace for reasons that are not related to their ability to do the job.²⁶ Regarding preemption of state law, according to the ULC, GINA has created general uncertainty about the enforceability of state genetic statutes in the

¹⁹ Uniform Protection of Genetic Information in Employment Act (2010).

²⁰ See *id.* Cisco McSorley introduced SB 445 on February 6, 2013, to the New Mexico 51st legislature.

²¹ See 2013 Regular Session: SB 445 Uniform Genetic Info in Employment Protection, New Mexico Legislature, <http://www.nmlegis.gov> (last visited 5/8/2014).

²² Cisco McSorley, Fiscal Impact Report SB 445, 3 (Feb. 15, 2013), <http://www.nmlegis.gov> (last visited 5/8/2014).

²³ *Id.*

²⁴ Protection of Genetic Information in Employment Act Summary, Uniform law Commission (2013), <http://www.uniformlaws.org> (last visited 5/7/2014).

²⁵ See *Id.*

²⁶ See *Id.*

context of employment.²⁷ Specifically, GINA currently preempts most state statutes that protect genetic information in employment because most existing state statutes fail to provide protection equal to or greater than federal law.²⁸ The ULC believes the UPGIEA must be passed as there is currently a lack of uniformity among existing state statutes, creating burdens on employers operating in more than one jurisdiction.²⁹

Highlights of the UPGIEA

The Uniform Act is designed to eliminate the preemption problems created by GINA for existing state statutes by incorporating the key definitions and concepts of GINA. It also complements and supplements GINA with provisions that are more protective of employees, following the pattern of many state fair employment laws that supplement Title VII³⁰ and other federal statutes. The Act comprehensively regulates acquisition, use, retention, and disclosure of genetic information in the employment setting.

The Uniform Act expands coverage beyond that of GINA in two principle ways. First, it closes a gap in GINA by extending coverage to entities that credential or license workers along with employers, unions, employment agencies, and training programs. Second, it includes employers with five or more employees, while giving states an option to extend coverage to smaller employers. This follows the pattern of state fair employment statutes, many of which cover smaller employers than those covered under Title VII.

The Act protects employees by requiring them to authorize employer acquisition of their genetic information and voluntary genetic testing as part of an employee wellness program or a genetic monitoring program. These authorization requirements are consistent with GINA, but are more specific. The Act sets forth the desirable content for authorization forms to give employers guidance and the assurance that they are following the law. It also allows employees to submit genetic information voluntarily so that it can be used for their protection, for example, in support of a request for reassignment to avoid a workplace substance to which a worker has a genetic susceptibility.

The Act supplements GINA with specific provisions on genetic testing, which is treated in GINA as part of the general category of acquisition of genetic information. The Act allows an employer to offer genetic testing only as part of a voluntary employee wellness program or a genetic monitoring program. It recognizes the importance of genetic counseling for employees' decisions to have a genetic test and in interpreting the results and requires genetic counseling before an employee or family member authorizes a genetic test and when a test predicts a disease or disorder unless the individual waives genetic counseling in writing. Since the Act recognizes that genetic counseling is an emerging profession that is not regulated in many states, it does not impose requirements on who may provide counseling. Therefore, unless there is state law to the contrary, counseling may be provided by physicians, geneticists, and nurse practitioners in addition to trained genetic counselors. The Act also regulates genetic testing by setting standards

²⁷ See *Id.*

²⁸ See *Id.*

²⁹ See *Id.*

³⁰ Civil Rights Act of 1964, 42 U.S.C. § 2000e et seq. (1964)

that require reporting the results to the employee, destroying the employee's biological sample and expunging genetic information produced ancillary to the test.

In order to prevent employment discrimination based on genetic information, the Act follows GINA by prohibiting specific actions based on genetic information, such as failure to hire, discharge, or discrimination in compensation or terms and conditions of employment. It also more comprehensively prohibits any adverse employment action against an employee based on the employee's genetic information. The Act incorporates GINA's provisions that make genetic information confidential and limit disclosures of that information. It supplements GINA by allowing employees to direct disclosures to third parties and by giving employees a specific right to inspect and copy genetic information in the employer's possession and to submit corrected information.

The enforcement and remedies section establishes a state-law private cause of action for violations of the Act. It allows a state to use its fair employment enforcement apparatus and offers the option to exhaust administrative remedies prior to a private lawsuit. In contrast to the provisions of GINA, states may enforce the Act and employees may file a cause of action based on a theory of disparate impact. Remedies are not limited to those authorized for Title VII, therefore federal caps on damages do not apply. Awards of attorney's fees generally follow federal law, are discretionary, and are authorized only for prevailing employees in order to cover the cost of enforcing the Act.

The Act allows states to use the enforcement mechanisms in place under their respective fair employment statutes. It eliminates preemption of state law under GINA and fosters uniformity among the states.³¹

Federal Law

GINA, which became law in 2008,³² "[p]rohibits use of an individual's genetic information by employers in employment decisions such as hiring, firing, job assignments, and promotions" and "[p]rohibits employers from requesting, requiring, or purchasing genetic information about an individual employee or family member."³³ GINA "[d]oes not subject employers to remedies and procedures that are any different from those in other civil rights laws such as Title VII and the Americans with Disabilities Act." Furthermore, GINA "[d]oes not prohibit workplace collection of genetic information for toxic monitoring programs, employer-sponsored wellness program, administration of federal and state Family and Medical Leave laws, and in certain cases of inadvertent acquisition of information." However, in these cases the employer may not use or disclose the information.³⁴

³¹ See *Id.*

³² GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, at 98-99 (2009).

³³ Genetic & Public Policy Center, Information on the Genetic Information Nondiscrimination Act (GINA), <http://www.dnapolicy.org> (last visited 5/8/2014).

³⁴ *Id.*

Under GINA, “genetic information” is defined as “information about: a person’s genetic tests; genetic tests of a person’s family members (up to and including fourth-degree relatives); any manifestation of a disease or disorder in a family member; participation of a person or family member in research that includes genetic testing, counseling, or education.” However, “genetic information” does not include information about sex or age.³⁵

A “genetic test” is defined by GINA as “a test that assesses genotypes, mutations, or chromosomal changes.” Examples of protected tests are: tests for BRCA1/BRCA2 (breast cancer) or HNPCC (colon cancer) mutations; classifications of genetic properties of an existing tumor to help determine therapy; tests for Huntington disease mutations; and carrier screening for disorders (e.g. screenings for cystic fibrosis, sickle cell anemia, spinal, muscular atrophy, and the fragile X syndrome). However, GINA does not protect routine tests such as complete blood counts (CBC, or blood panel), cholesterol tests, and liver-function tests or analysis—including DNA analysis—of infectious agents such as bacteria, viruses, and fungi. For example, an HIV test is not covered by GINA.³⁶

GINA does not apply to members of the United States Military, to veterans obtaining health care through the Veteran’s Administration, or to the Indian Health Service.³⁷ Nor does GINA include protection from genetic discrimination in life insurance, disability insurance, or long-term-care insurance.³⁸ GINA affects—and differs from—current federal anti-discrimination laws.³⁹ While the Americans with Disabilities Act contains an exception that allows an employer, in special circumstances, to make a decision based on information that would otherwise be protected, GINA does not allow for an exception.⁴⁰ Furthermore, under GINA, prohibitions contained in the Employee Retirement Income Security Act (“ERISA”) extend to genetic information.⁴¹ Finally, GINA expands the protections of the Health Insurance Portability and Accountability Act (“HIPAA”) by requiring “that all genetic information be treated as health information under HIPAA, thus making this information subject to HIPAA’s privacy regulations.”⁴²

Importance of Promoting Genetic Testing and Research

While there are enormous opportunities made possible by genetic testing, such as precautionary measures and early diagnosis, fear of genetic discrimination may cause many to avoid genetic testing.⁴³ Moreover, without protection of genetic information, individuals may avoid genetic tests because of privacy concerns. “Tests designed to determine the presence or version of genes that cause diseases or conditions carry with them the most intimate details of an

³⁵ *Id.*

³⁶ *Id.*

³⁷ *Id.*

³⁸ *Id.*

³⁹ GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, at 99 (2009).

⁴⁰ *Id.*

⁴¹ *Id.*

⁴² *Id.*

⁴³ GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, at 96 (2009).

individual's biological past and future, and also provide information about parents, siblings and children that impacts on family privacy."⁴⁴

It has been said that it is important to encourage individuals to be willing to take genetic tests, and that employers' reliance on genetic tests in employment decision-making is highly questionable. First, genetic tests do not absolutely predict an individual's future. Most genetic markers are not conclusively diagnostic.⁴⁵ Rather, they "may indicate a predisposition to a particular disease or condition, or may presently be believed to have a correlation with a particular disease or condition."⁴⁶ Despite this fact, employers may incorrectly believe that "the presence of a genetic mutation is an 'unalterable prediction that a person will manifest the associated disorder.'"⁴⁷ These misplaced beliefs about the meaning of genetic tests have caused numerous individuals to avoid genetic testing and research participation because of "fears that employers and insurance companies would access the information and use it to discriminate against those individuals."⁴⁸ Moreover, despite the potential benefits of genetic tests, including avoiding premature death, "Americans feel so unprotected by genetic information confidentiality regulations that they are willing to decline such testing."⁴⁹

Furthermore, there are reasons to question the accuracy of some tests. No single government entity oversees or regulates genetic testing, and the current regulatory structure allows genetic testing manufacturers and laboratories to operate without any real standards.⁵⁰ This has led some to believe that "there is an unjustified risk that inaccurate genetic tests may be used to lawfully discriminate against people because of weak government regulations in the areas of confidentiality and genetic test quality control."⁵¹

GINA's Limitations

The regulations promulgated in accordance with GINA have not extended HIPAA very far.⁵² GINA requires the Department of Health and Human Services to revise the relevant privacy regulations under HIPAA to include genetic information as protected health information.⁵³ However, under HIPAA, genetic information is already protected health information.⁵⁴ Instead of revising the definition of protected health information, it has been suggested that GINA should have aimed to revise the definition of covered entities and to revise statutorily-created exceptions.⁵⁵

⁴⁴ Jane Massey Licata, Keeping a Lid on Pandora's Box: Strategies for Protecting Genetic Privacy, 245-Apr. N.J. Lawyer 9, 10 (2007).

⁴⁵ *Id.* at 9.

⁴⁶ *Id.*; see also Amy Foster, Critical Dilemmas in Genetic Testing: Why Regulations to Protect the Confidentiality of Genetic Information Should Be Expanded, 62 Baylor L. Rev. 537, 546 (2010).

⁴⁷ Amy Foster, Critical Dilemmas in Genetic Testing: Why Regulations to Protect the Confidentiality of Genetic Information Should Be Expanded, 62 Baylor L. Rev. 537, at 546 (2010).

⁴⁸ *Id.*

⁴⁹ *Id.*, at 546.

⁵⁰ *Id.*, at 561.

⁵¹ *Id.* at 561.

⁵² *Id.* at 547.

⁵³ *Id.* at 547.

⁵⁴ *Id.* at 547.

⁵⁵ *Id.* at 547.

Congress modeled the enforcement and damages provisions applicable to violations of GINA after Title VII of the Civil Rights Act of 1974 and other federal laws meant to prevent and punish employment-based discrimination.⁵⁶ GINA's incorporation of Title VII has narrowed GINA's effect on discriminatory employment practices because Title VII's definition of employer exempts entities not affecting commerce or with fifteen or fewer employees.⁵⁷ If the employer or potential employer does not affect commerce or does not have more than fifteen employees, employees and potential employees will have no remedy against them.⁵⁸ Further, individuals claiming that they were discriminated against by their employer or a potential employer must first file a complaint with the Equal Employment Opportunity Commission ("EEOC") before filing suit under GINA.⁵⁹

In addition, GINA is restricted by Congress' decision to bar lawsuits based upon the theory of disparate impact for at least six years.⁶⁰ In May 2014, a Genetic Nondiscrimination Study Commission will form to "review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action" under GINA."⁶¹ Congress' decision to eliminate disparate impact theory at this point will severely restrict GINA's actual impact because it is very difficult to prove intentional discrimination.⁶²

Finally, it has been suggested that GINA will be limited because it contains loopholes that permit genetic information to be shared with employers and other entities.⁶³ For example, under the Family and Medical Leave Act of 1993 ("FMLA"), an employer can potentially gain lawful access to genetic information to certify the health status of an employee who seeks medical leave under FMLA.⁶⁴ In addition, GINA permits "genetic monitoring," which allows employers in some situations to require employees or family members to submit to regular genetic testing to monitor the biological effects of toxic substances in the workplace.⁶⁵ Under exceptions, such as genetic monitoring, employers will be legally permitted to gather genetic information.⁶⁶ While the employer is not legally permitted to use this information for discriminatory purposes, an employer might do because it would be very difficult for an employee to bring suit, particularly in the absence of the disparate impact theory.⁶⁷

⁵⁶ *Id.*, at 546.

⁵⁷ *Id.* at 548 (citing 42 U.S.C.S. § 2000e(b)).

⁵⁸ *Id.* at 548 (citing 42 U.S.C.S. § 2000e(b)).

⁵⁹ *Id.* at 548.

⁶⁰ *Id.* at 548 (citing 42 U.S.C. § 2000ff-7). "Disparate impact refers to a type of discrimination whereby policies that appear neutral on their face actually disproportionately impact a protected class regardless of the intent to discriminate or lack thereof by the policymakers." *Id.* (citing *Griggs v. Duke Power Co.*, 401 U.S. 424, 430 (1971)).

⁶¹ *Id.* 548 (citing 42 U.S.C.S. § 2000ff-7(b)).

⁶² Amy Foster, Critical Dilemmas in Genetic Testing: Why Regulations to Protect the Confidentiality of Genetic Information Should Be Expanded, 62 *Baylor L. Rev.* 537, at 548-49 (2010).

⁶³ *Id.* at 549.

⁶⁴ *Id.* at 549 (citing 42 U.S.C. § 2000ff-1(b)(3)).

⁶⁵ *Id.* at 549 (citing 42 U.S.C. § 2000ff-1(b)(5)).

⁶⁶ *Id.* at 549-50 (citing 42 U.S.C.S. §§ 2000ff-1, ff-7).

⁶⁷ *Id.*

Confusion Regarding the Interaction between GINA and the GPA

Articles written about this issue have said that it is unclear how GINA and the GPA interact.⁶⁸ GINA currently preempts most of the state statutes that protect genetic information in employment because the state statutes fail to provide protection equal to or greater than the federal statute.⁶⁹ Because of New Jersey's comprehensive protection of genetic information under the GPA, it is unlikely that GINA will provide more protection than current New Jersey laws,⁷⁰ and therefore GINA does not likely preempt provisions of the GPA. However, as the ULC correctly notes, New Jersey's adoption of the UPGIEA would eliminate concerns about preemption of New Jersey law under GINA and could assist with uniformity among the states.⁷¹ Elimination of confusion is critical in reducing the burden on employers who operate in more than one jurisdiction.

Further Considerations

Because New Jersey has already enacted the GPA, which provides extensive protections, it may be more legislatively palatable to amend the GPA to import protective language now found in the UPGIEA than to enact a separate UPGIEA. If the Commission chooses to do so, it may wish to consider amending some sections of the UPGIEA and eliminating or limiting some of the exceptions contained in the Act. The unsuccessful bill to adopt the UPGIEA in New Mexico, raised the number of qualifying employees from five to fifteen in the definition of "employee,"⁷² to make the bill more palatable to those concerned about imposing undue burdens on small businesses. In that bill, agents of an employer and employment agency were included within the scope of the Act,⁷³ as a way of providing greater protection for the citizens. Finally, the New Mexico bill provided guidance to employers regarding the actions to take upon learning they inadvertently acquired genetic information⁷⁴ and a safe harbor provision could benefit similarly situated New Jersey businesses.

⁶⁸ GINA Will Protect You, Just Not from Death: The Genetic Information Nondiscrimination Act and Its Failure to Include Life Insurance Within Its Protections, 34 Seton Hall Legis. J. 93, at 104 (2009).

⁶⁹ Protection of Genetic Information in Employment Act Summary, Uniform Law Commission (2013), <http://www.uniformlaws.org> (last visited 5/7/2014).

⁷⁰ *Id.*

⁷¹ *Id.*

⁷² See Cisco McSorley, Fiscal Impact Report SB 445, 3 (Feb. 15, 2013), <http://www.nmlegis.gov> (last visited 5/8/2014).

⁷³ *Id.*

⁷⁴ *Id.*