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I DREAM OF GINA: UNDERSTANDING THE EMPLOYMENT PROVISIONS OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008

WILLIAM J. McDEVITT, ESQ.*

I. INTRODUCTION

THE news could not have been more devastating. Sarah had reconciled herself to the untimely death of her brother. His drinking problem over the past few years, as well as his general disinterest in taking care of his basic needs, surely led to his downward spiraling health and, ultimately, his demise in a sterile intensive care unit. But she could not understand why the doctor had ordered a genetic test upon his death. What did the doctor suspect that no one else saw?

The test results came back: her brother had a faulty gene on chromosome 4, the marker for Huntington's disease.¹ This explained his involuntary shakes, weight loss, and difficulty speaking, and it also may have explained his rather quick demise as the organs in his body shut down.² Even more disturbing and frightening, the positive test result meant that Sarah and her siblings had a fifty percent chance of developing the disease themselves, not to mention the children of those among her brothers and sisters who had also tested positive.³ In addition, if Sarah herself had tested positive—and if her employer discovered that she had—she stood a good chance of being fired from her well-paying job.⁴

While the foregoing is only a hypothetical scenario, its implications are all too real. Sarah's fears were neither feigned nor fanciful. There currently is no effective, clear legal prohibition against employment dis-

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1. See HUNTINGTON'S DISEASE ASS'N, GENERAL INFORMATION ABOUT HUNTINGTON'S DISEASE, *Fact Sheet 2* (2008), available at <http://www.hda.org.uk/download/factsheets/HD-Huntingtons-Disease.pdf> (explaining cause of Huntington's disease).

2. See *id.* (describing symptoms that occur as disease progresses).

3. See *id.* ("Each person whose parent has Huntington's disease is born with a 50:50 chance of inheriting the faulty gene."). Although genetic testing will indicate whether individuals have inherited the faulty gene, testing will not be able to determine the age at which they will develop Huntington's disease. See *id.* (describing limits of genetic test for Huntington's disease).

4. See generally Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 2 (1994) ("The advent of such genetic information creates the fear that this knowledge will be turned against those with undesirable conditions.").

crimination on the basis of genetic information or defects, outside of employment with the federal government.⁵

Prior legislation designed to end discrimination in the workplace, including the Civil Rights Act of 1964⁶ and the Americans With Disabilities Act of 1990 (ADA),⁷ does not specifically address employment discrimination based on genetic information. Despite intending the ADA to provide a comprehensive scheme of protection against discrimination on the basis of disability, legislators drafted the ADA at a time when our understanding of genetics, as well as our ability to detect and predict disorders stemming from genetics, was in its infancy. Congress recognized that this lack of understanding at the time of the ADA's passage resulted in a deficiency in protection against discrimination on the basis of individuals' genetic makeup. Congress has attempted to remedy this deficiency in protection by passing the Genetic Information Nondiscrimination Act of 2008 (GINA).⁸

This Article analyzes the deficiencies in federal law that precipitated Congress's passage of GINA, and offers a detailed explanation of GINA's provisions. Part II explains how genetic information can be used to discriminate against employees.⁹ Part III explores Congress's intent to include genetic defects within the protections provided by the ADA.¹⁰ Part IV reviews how, despite Congress's intent, the language of the ADA fails to take into account various scenarios under which employees can face genetic discrimination.¹¹ Part V provides an overview of GINA, which is designed to protect employees from discrimination based on their genome more definitively than the ADA.¹² Finally, Part VI identifies several congressional compromises made in the course of drafting GINA, and discusses the potential impact of these compromises in subsequent applications of the new legislation.¹³

5. See Exec. Order No. 13,145, 3 C.F.R. 235 (2001), *reprinted in* 42 U.S.C. § 2000e-1(b) (2006) (prohibiting discrimination, based on protected genetic information, against federal government employees).

6. 42 U.S.C. §§ 2000e to 2000e-17 (2006).

7. 42 U.S.C. §§ 12101-12213 (2006).

8. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (to be codified at 42 U.S.C. §§ 2000ff to 2000ff-11). GINA will take effect on November 21, 2009, eighteen months after its enactment. See *id.* § 213 (listing statute's effective date).

9. For an account of how employers can use genetic information to discriminate against employees, see *infra* notes 22-30 and accompanying text.

10. For an analysis of Congress's intent that the protections of the ADA apply to individuals with genetic defects, see *infra* notes 31-43 and accompanying text.

11. For a discussion of the ADA's inability to extend to several possible scenarios of genetic discrimination, see *infra* notes 44-88 and accompanying text.

12. For a comprehensive overview of GINA, see *infra* notes 89-131 and accompanying text.

13. For a discussion of the compromises Congress made in order to ensure enactment of GINA, see *infra* notes 132-40 and accompanying text.

II. GENETICS AND DISCRIMINATION

A. *A Primer on Genetics*

A human being is an "organism," which means that it is composed of various organs such as the heart, brain, liver, kidney, hair, and skin. The organs, in turn, are made up of cells. Each cell contains a "nucleus" which houses genetic material. The genetic material is stored in thread-like structures called "chromosomes."¹⁴

A human being has twenty-three pairs of chromosomes in each cell, for a total of forty-six chromosomes.¹⁵ These chromosomes hold our genes.¹⁶ A "gene" is a unit of deoxyribonucleic acid (DNA) that carries the instructions for making a specific protein or set of proteins.¹⁷ A human being is made up of an estimated 20,000 to 25,000 genes.¹⁸

Collectively, all of an individual's genes are known as that individual's "genome."¹⁹ Each gene within a genome is responsible for a particular function or trait, such as hair color and blood type.²⁰ These same genes, however, can cause serious or fatal diseases or conditions when they are abnormal or defective.²¹

B. *Employer Discrimination on the Basis of Genetics*

The question arises: Should employers be allowed to discriminate against job applicants or employees based upon their individual genetic

14. See National Human Genome Research Institute, Chromosomes, <http://www.genome.gov/26524120> (last visited Nov. 18, 2008) (providing definition of chromosome).

15. See *id.* (providing number of chromosomes in humans). By comparison, a fruit fly has four pairs of chromosomes, whereas a dog has thirty-nine. See *id.* (comparing number of chromosomes in humans to number of chromosomes in other species).

16. See National Human Genome Research Institute, Chromosome Abnormalities, <http://www.genome.gov/11508982> (last visited Nov. 18, 2008) (describing chromosomes' function).

17. See National Human Genome Research Institute, A Brief Guide to Genomics, <http://www.genome.gov/18016863> (last visited Nov. 18, 2008) (defining "gene").

18. See *id.* (estimating number of genes in human genome).

19. See National Human Genome Research Institute, An Overview of the Human Genome Project, <http://www.genome.gov/12011238> (last visited Nov. 18, 2008) (defining "genome").

20. See Chromosomes Abnormalities, *supra* note 16 (describing chromosomes' specific function).

21. See Kristie A. Deyerle, Comment, *Genetic Testing in the Workplace: Employer Dream, Employee Nightmare—Legislative Regulation in the United States and the Federal Republic of Germany*, 18 COMP. LAB. L.J. 547, 551 (1997) (describing effects of genetic variation). Three to four percent of newborns possess genetic or congenital defects. See *id.* (noting that genetic variations "are not that uncommon"). All individuals possess between five and seven lethal recessive genes, as well as an undetermined number of genes that can predispose their carriers to diseases in the future. See *id.* at 556 (indicating that although all individuals possess lethal recessive genes, these genes do not cause genetic diseases in all individuals).

codes?²² Considering that genes dictate individuals' physical characteristics and much of their mental abilities, it is apparent that many employers can and do discriminate on the basis of genetics. Moreover, there are few legal restrictions preventing employers from engaging in genetic discrimination. No law prevents employers from favoring job applicants or employees because of their height, size, muscle structure, hair color, eye color, or even intelligence—all of which are partially or totally determined by genes.²³ Instead, employers violate the law only by discriminating on the basis of individuals' genetically dictated skin color, race, or sex.²⁴ This discrepancy in legal treatment is based on the fact that few employers, if any, stigmatize physical characteristics such as hair, eye color, or even size, whereas there is a long history of prejudice on the basis of sex, race, and color.

The question, therefore, is not whether discrimination based upon an individual's genetic code should be allowed. Rather, the better question is whether the law should permit discrimination against individuals based upon actual or perceived genetic variations from the "normal" human genotype.²⁵ From this perspective, several genetically related scenarios

22. See Nicole Silvestri, Comment, *Echazabal and the Threat to Self-Defense: The Most Recent Call for a Consistent, Interstate Genetic Nondiscrimination Policy*, 7 U. PA. J. LAB. & EMP. L. 409, 412-13 (2005) (noting pros and cons of prohibiting employers from making hiring decisions based upon genetic information). Agreeing on a definition of "genetic discrimination" is a challenge in and of itself. See *id.* at 411 (noting that experts disagree on definition of "genetic discrimination"). Nonetheless, Silvestri adopted a definition proposed by Robert Olick, an expert in both law and bioethics. See *id.* Olick has suggested that genetic discrimination is "negative differential treatment of an individual based solely upon that person's possession of one or more genetic traits that deviate from the "normal" genome, or on the perception that the individual possesses one or more genetic traits that deviate from the "norm," when that person is asymptomatic." *Id.* at 411-12 (quoting Robert S. Olick, *Genes in the Workplace: New Frontiers for ADA Law, Policy, and Research, in EMPLOYMENT, DISABILITY, AND THE AMERICANS WITH DISABILITIES ACT 285, 288* (Peter David Blanck ed., 2000)).

23. See 29 C.F.R. pt. 1630, app. § 1630.2(h) (2007) ("The definition of the term 'impairment' does not include physical characteristics such as eye color, hair color, left-handedness, or height, weight or muscle tone that are within 'normal' range and are not the result of a physiological disorder."). The United States Supreme Court has endorsed this position, stating:

[A]n employer is free to decide that physical characteristics or medical conditions that do not rise to the level of an impairment—such as one's height, build, or singing voice—are preferable to others, just as it is free to decide that some limiting, but not *substantially* limiting, impairments make individuals less than ideally suited for a job.

Sutton v. United Air Lines, Inc., 527 U.S. 471, 490-91 (1999).

24. See 42 U.S.C. §§ 2000e to 2000e-17 (2006) (prohibiting discrimination by employers with fifteen or more employees on basis of race, color, religion, sex, and national origin).

25. See Epstein, *supra* note 4, at 2-3 (asking whether prominent institutions in society should be able "to take into account genetically derived information that reveals an individual's prospects for future disease and incapacity"). Epstein adopted the definition of genetic discrimination formulated by Paul R. Billings, who described it as "discrimination directed against an individual or family based

can arise that tend to expose an individual to discrimination. They are: (1) abnormal physical traits—such as height, weight, and size; (2) symptomatic genetic disease; (3) asymptomatic, late-onset genetic disease; (4) asymptomatic genetic predisposition to disease; and (5) the unaffected carrying of a genetic disorder.²⁶

Any one of these five scenarios could expose an individual to discrimination in the workplace. Most employers, concerned about productivity and costs such as health benefits and life insurance, would tend to eschew a job applicant who either has or will have a genetically related disorder, or who has a heightened risk of developing one.²⁷ In the case of abnormal physical traits and symptomatic genetic diseases, the ADA provides relatively clear guidance as to whether such individuals would meet the definition of “disability,” and would thus fall within the statute’s protection.²⁸ In contrast, for asymptomatic individuals who will or might develop genetic diseases, or who might pass them to offspring, coverage under the ADA is uncertain.²⁹ It is precisely these types of individuals who may now be identified with increased accuracy through the genetic testing

solely on an apparent or perceived genetic variation from the “normal” human genotype.” See *id.* at 3 (quoting Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 476 (1992)). Another commentator has used a definition of “genetic discrimination” that includes only asymptomatic individuals. See Deyerle, *supra* note 21, at 556 (“Genetic discrimination can be distinguished from traditional disability-based discrimination in that the former category includes only discrimination against those who are visibly asymptomatic at the time of the discretionary act.”).

26. But see Mark A. Rothstein, *Genetic Discrimination in Employment and the Americans with Disabilities Act*, 29 HOUS. L. REV. 23, 39-52 (1992) (providing seven genetic categories). Rothstein has termed his categories as follows: (1) “already-expressed genetic diseases;” (2) “already-expressed minor genetic conditions;” (3) “unexpressed late-onset genetic diseases;” (4) “genetic predisposition/increased risk;” (5) “unaffected carrier of recessive and X-linked disorders;” (6) “having a record of genetic disease;” and (7) “regarded as having a genetic condition.” See *id.* (formulating categories of genetic scenarios).

27. See Stacey J. Bagley, Comment, *Enough is Enough! Congress and Courts React to Employers’ Medical Screening and Surveillance Procedures*, 99 DICK. L. REV. 723, 725-26 (1995) (explaining reasons why employers may engage in medical screening and surveillance). There is a seemingly unavoidable tension between the interests of employees and those of employers: employees want jobs, dignity, reputation, and legal rights, whereas employers need greater productivity. See *id.* at 723. Furthermore, employers must be concerned about the liability they accept when they hire physically or mentally unfit individuals. See *id.* (noting conflicting interests at stake in debate over whether to permit genetic discrimination).

28. See 42 U.S.C. § 12102(2) (2006) (defining “disability”). Specifically, the ADA defines “disability” as: “(A) a physical or mental impairment that substantially limits one or more of the major life activities . . . ; (B) a record of such impairment; or (C) being regarded as having such an impairment.” *Id.*

29. See Brian R. Gin, Note, *Genetic Discrimination: Huntington’s Disease and the Americans with Disabilities Act*, 97 COLUM. L. REV. 1406, 1419 (1997) (“No court has yet addressed the question of whether genetic conditions are disabilities under the ADA . . .”).

and screening made possible by successful completion of the Human Genome Project.³⁰

III. GENETIC DISCRIMINATION AND THE ADA

Passage of the ADA seemingly settled the question of whether, as a matter of public policy, employers should be allowed to discriminate against job applicants or employees based upon their individual genetic codes. In its report to Congress, the United States House of Representatives Committee on Education and Labor, which considered the bill that became the ADA, stated:

In conclusion, there is a compelling need to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities and for the integration of persons with disabilities into the economic and social mainstream of American life. Further, there is a need to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities. Finally, there is a need to ensure that the [f]ederal [g]overnment plays a central role in enforcing these standards on behalf of individuals with disabilities.³¹

From this sweeping statement of the statute's ultimate purpose, it can be inferred that Congress intended that the ADA cover individuals with both extant and inchoate disabilities.³² Apparently, the ADA is designed to eliminate discrimination against all "individuals with disabilities."³³ In defining "disability," the House Committee listed muscular dystrophy and multiple sclerosis—two diseases rooted in genetic aberrations—as examples of conditions, diseases, and infections that would constitute physical

30. See A Brief Guide to Genomics, *supra* note 17 (explaining Human Genome Project and its contributions to genetics). Completed in 2003, the Human Genome Project determined the order of, or "sequenced," all three billion base pairs of deoxyribonucleic acid (DNA) that make up the human genome. See *id.*

31. H.R. REP. NO. 101-485, pt. 2, at 50 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 451. This policy was codified in the "Purpose" clause of the Americans with Disabilities Act. See 42 U.S.C. § 12101(b) (2000) (adopting language of House Report as purpose of statute).

32. See § 12101(b) (setting forth broad goals of ADA to eliminate discrimination based on disability). Although Congress could have inserted language in the ADA directly dealing with genetic conditions, it appears from the definition of the term "disability" that Congress instead focused on existing past or present impairments. See Rothstein, *supra* note 26, at 39 ("Congress enacted the ADA without any serious consideration about the law's effect on individuals with various genetic conditions. The ADA itself is silent on the issue, as are the EEOC implementing regulations. Only brief mentions of genetic disabilities are made in the voluminous legislative history.") (footnotes omitted).

33. See § 12101(b)(2) (describing one purpose of statute).

impairments.³⁴ Because job applicants suffering from multiple sclerosis are disabled, and therefore protected under the ADA, the statutory language suggests that job applicants who carry genes that will or may cause multiple sclerosis are likewise disabled.³⁵

The ADA also suggests that the latent nature of certain genetic diseases should not disqualify individuals from being considered disabled. The House Committee specifically included a person infected with the Human Immunodeficiency Virus (HIV) in its examples of individuals who are disabled under the ADA.³⁶ It is difficult to justify considering asymptomatic, HIV-infected individuals “disabled” under the ADA while not granting the same status to individuals who bear genetic defects that will cause, for example, Huntington’s disease.³⁷

The very mechanics of the job application process indicate that Congress intended the ADA to cover individuals with eventually or potentially disabling genetic defects. Some aspects of an individual’s genetic makeup are obvious upon observation. For example, attributes such as hair color, skin color, eye color, height, and facial features—all of which are genetically determined—are readily observable by most prospective employers. The rest of an individual’s genomes, however, are hidden within the chromosomes of that individual’s cells. Employers, therefore, could only learn about the bulk of job applicants’ or employees’ genetic makeup—including the applicants’ or employees’ predisposition to various diseases—through genetic screening.³⁸

34. See H.R. REP. NO. 101-485, pt. 2, at 51 (explaining definition of “disability”); see also Deyerle, *supra* note 21, at 571 (citing § 12211) (noting that certain conditions that are arguably genetic—such as homosexuality, bisexuality, and kleptomania—are specifically excluded from ADA’s definition of disability).

35. See George P. Smith, II & Thaddeus J. Burns, *Genetic Determinism or Genetic Discrimination?*, 11 J. CONTEMP. HEALTH L. & POL’Y 23, 25 (1994) (“Unlike information about a specific transient condition or illness, data pointing to a genetic disorder will affect, and may stigmatize, a person throughout his or her life.”).

36. See H.R. REP. NO. 101-485, pt. 2, at 52 (explaining definition of disabled). The Supreme Court later confirmed that HIV-positive individuals are considered disabled under the ADA. See *Bragdon v. Abbott*, 524 U.S. 624, 631 (1998) (holding that HIV qualifies as disability under ADA).

37. See generally Gin, *supra* note 29, at 1422-24 (analogizing Huntington’s disease to HIV infection for purposes of ADA protections). Specifically, Gin noted three similarities between HIV-positive status and Huntington’s disease, which he believed support the argument that Huntington’s disease—like HIV—should be considered a disability under the ADA:

First, predictive tests for both diseases are extremely accurate and precise. Second, at the time of diagnosis, victims of both conditions may have no symptoms and may remain healthy for many years. Finally, although the exact time of onset is unascertainable, death within a given range of years is extremely likely, if not certain.

Id. at 1423 (footnotes omitted).

38. See Deyerle, *supra* note 21, at 554 (discussing differences between genetic testing, screening, and monitoring). Genetic screening involves a test that can determine whether a person either has a genetic condition that predisposes towards development of a particular disease, or carries a genetic defect that could be

The ADA prohibits such medical examinations and other inquiries that could reveal job applicants' genetic defects before offers of employment are extended.³⁹ Underlying this prohibition is the goal of preventing employers from excluding job applicants before the applicants' abilities to perform their potential jobs are evaluated.⁴⁰ Again, it stretches the rules of logic to conclude that Congress would prohibit pre-offer medical examinations or inquiries that could reveal genetic disease or defects—or propensities for such diseases—but permit employers to discriminate against qualified individuals on account of their genetic information.⁴¹ It appears that, to Congress, the possibility of future incapacity does not by itself render individuals unqualified for presently available positions.⁴²

In summary, the ADA appears to prohibit employers from discriminating against job applicants or employees based upon their individual genetic codes. Congress intended the ADA to prohibit discrimination against qualified individuals who are disabled. Congress also intended that the term “disability” include both extant and inchoate conditions. If individuals who suffer from diseases that substantially limit major life functions are protected under the ADA, then individuals who will or may suffer in the future from the same diseases by virtue of genetic defects should likewise be protected.

The fact that genetic diseases are latent should be of no more legal consequence than the fact that HIV-infected individuals have not yet developed AIDS. Indeed, the Equal Employment Opportunity Commission (EEOC), the agency charged with implementing Title I of the ADA, endorsed the extension of the statute to individuals who are subject to dis-

transmitted to that person's offspring. *See id.* (defining genetic screening). Some of the more than 4,000 known genetic diseases are cystic fibrosis, Duchenne muscular dystrophy, Huntingdon's chorea disease, juvenile diabetes, Lesch-Nylan disease, sickle cell anemia, phenylketonuria, and hemochromatosis. *See* Epstein, *supra* note 4, at 2 (detailing advances in field of genetic testing).

39. *See* 42 U.S.C. § 12112(d)(2)(A) (2006) (providing that employers may not “conduct a medical examination or make inquiries of job applicants as to whether the applicants have disabilities or as to the nature or severity of such disabilities”).

40. *See* H.R. REP. NO. 101-485, pt. 2, at 72 (detailing ways in which employers have historically engaged in genetic discrimination). Specifically, legislative history indicates that the ADA sought to eliminate the practice where:

[E]mployment application forms and employment interviews requested information concerning an applicant's physical or mental condition. This information was often used to exclude applicants with disabilities—particularly those with so-called hidden disabilities such as epilepsy, diabetes, emotional illness, heart disease and cancer—before their ability to perform the job was even evaluated.

Id.

41. *See* § 12111(8) (providing that “qualified” individuals are those who can perform “essential functions” of employment positions “with or without reasonable accommodation”).

42. *See* H.R. REP. NO. 101-485, pt. 2, at 55 (explaining that “[t]he term ‘qualified’ refers to whether the individual is qualified at the time of the job action in question; the possibility of future incapacity does not by itself render the person not qualified”).

crimination on the basis of genetic information relating to illness, disease, or other disorders.⁴³ Although the ADA appears to prohibit genetic discrimination, an analysis of its application to certain genetic scenarios leads to a far different conclusion.

IV. DEFICIENCIES IN APPLYING THE ADA TO GENETIC DISORDERS

If Congress intended to protect individuals who carry discernible genetic defects from discrimination in the workplace, does the ADA, in fact, provide such protection? By its own terms, the statute purports to protect every "qualified individual with a disability."⁴⁴ Under the ADA, a "disability" is "(A) a physical or mental impairment that substantially limits one or more of the major life activities . . . ; (B) a record of such an impairment; or (C) being regarded as having such an impairment."⁴⁵ Unfortunately, despite the statute's broad statement of purpose, this definition does not seem to apply very well to the five genetically related scenarios identified in Part II.⁴⁶

A. *Abnormal Physical Traits*

The physical traits of human beings are dictated primarily by their genes. For example, hair color, eye color, skin color, height, and size are largely, if not exclusively, determined by genes. Typically, such physical characteristics are not considered impairments that would constitute disabilities under the ADA. Such is the case, provided that expression of these characteristics falls within a range for expression defined under the ADA as "normal."⁴⁷

43. See U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, COMPLIANCE MANUAL § 902.8 (1992), available at <http://www.eeoc.gov/policy/docs/902cm.html> (calling for application of ADA to genetic discrimination). Specifically, the EEOC stated:

[The "regarded as having an impairment"] part of the definition of "disability" applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of "disability."

Id. This is a reversal of the EEOC's original position, which held that the definition of disability did not include "characteristic predisposition to illness or disease." See 29 C.F.R. pt. 1630, app. § 1630.2(h) (2007) (providing guidance on meaning of disability under ADA).

44. See 42 U.S.C. § 12111(8) (providing definition of "qualified individual with a disability").

45. See § 12102(2) (providing definition of "disability").

46. For a discussion of how and why discrimination based on genetic information may occur in the workplace, and for an identification of five specific scenarios in which such discrimination may occur, see *supra* notes 22-30 and accompanying text.

47. See H.R. REP. NO. 101-485, pt. 2, at 51 (defining "disability" under ADA); H.R. REP. NO. 101-485, pt. 3, at 28 (defining "physical impairment" under ADA);

When a physical trait is abnormal, however, individuals possessing such trait may be considered “disabled” under the ADA under two possible theories. First, the abnormal physical trait may constitute a physical impairment “that substantially limits one or more major life activities of [the possessing] individual.”⁴⁸ For example, individuals who are morbidly obese as a result of genetic defects—where their obesity substantially limits their ability to walk—would qualify as disabled under the first prong of the ADA’s definition of “disability.”⁴⁹

As an alternative, individuals who have abnormal physical traits may be disabled because they are “regarded as having [a substantially limiting] impairment.”⁵⁰ For example, people who stand four feet, five inches high as a result of a genetic defect known as achondroplastic dwarfism may be treated by their employers as having a substantially limiting impairment. Although dwarfism itself does not substantially limit any major life activity, employers treating the condition as if it does renders those with the condition disabled under the ADA.⁵¹ In short, for individuals who possess abnormal physical traits as a result of genetic defects, the ADA clearly provides protection by including them within either the first or second prong of the definition of “disability.”

B. *Symptomatic Genetic Disease*

Whether individuals who are suffering symptoms from genetic diseases are disabled under the ADA depends upon the severity of the impact of such symptoms on those individuals’ lives. Specifically, the impairments

29 C.F.R. pt. 1630, app. § 1630.2(h) (stating that, under ADA, definition of term “impairment” does not include physical characteristics, provided that such characteristics are within “normal” range and not resulting from physiological disorder).

48. 42 U.S.C. § 12102(2)(A) (describing limiting characteristic of physical impairment). Under this prong of the ADA’s definition of disability, the fact that individuals have physical or mental impairments is not enough to meet the statutory criteria. See William J. McDevitt, *Defining the Term Disability Under the Americans with Disabilities Act*, 10 ST. THOMAS L. REV. 281, 285-88 (1998) (discussing physical or mental impairment prong of ADA’s definition of disability). The impairments must also substantially limit the individuals’ ability to engage in major life activities such as seeing, walking, hearing, speaking, or working. See *id.*

49. Cf. *Cook v. R.I., Dep’t of Mental Health, Retardation, & Hosps.*, 10 F.3d 17, 23 (1st Cir. 1993) (stating that jury could view obesity as impairment that interfered with major life activities); see also Steven M. Ziolkowski, Comment, *The Status of Weight-Based Discrimination Under the Americans with Disabilities Act After Cook v. Rhode Island Department of Mental Health, Retardation, and Hospitals*, 74 B.U. L. REV. 667, 680-83 (1994) (providing exhaustive analysis of *Cook*).

50. See § 12102(2)(C) (listing “regarded as having such an impairment” as one of three bases under which individual is deemed disabled).

51. See *Dexler v. Tisch*, 660 F. Supp. 1418, 1429 (D. Conn. 1987) (finding that dwarfism constitutes substantially limiting impairment). Although *Dexler* concerned Title V of the Rehabilitation Act of 1973, 29 U.S.C. §§ 791-794 (2006), and not the ADA, Congress has directed that the ADA cannot be construed to apply a lesser standard than the Rehabilitation Act and its regulations. See 42 U.S.C. § 12201(a) (2006) (instructing courts on how to interpret ADA).

that result from genetic diseases must substantially limit one or more of sufferers' major life activities.⁵² Under the ADA, major life activities are the basic activities "that the average person in the general population can perform with little or no difficulty."⁵³ They include basic functions such as "caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working."⁵⁴ Reproduction and intimate sexual relationships also fall within this category.⁵⁵

Impairments fall into two categories: those that are substantially limiting per se and those that are substantially limiting for particular individuals. Individuals who are blind, deaf, or paralyzed are substantially limited by their conditions, regardless of their individual situations. For less severe impairments, however, consideration is given to the severity, duration, and permanency of the unique impacts of the impairments on particular suffering individuals.⁵⁶ Under the ADA, therefore, neither severe but short-lived impairments—such as broken bones—nor chronic but mild impairments—such as myopia—are considered disabilities.

Based on these principles, individuals who suffer from symptomatic genetic diseases must show either that their diseases are per se substantially limiting or that their symptoms are of such severity and duration that they are substantially limited in their abilities to engage in recognized major life activities in order to qualify under the first prong of the ADA's definition of "disability." Thus, individuals in the latter stages of Huntington's chorea—a hereditary disease characterized by chronic, ceaseless, and involuntary jerky movements as well as mental deterioration that terminates in dementia—would surely be considered disabled.⁵⁷ Individuals who have not yet experienced symptoms, however, would not.⁵⁸

52. See § 12102(2)(A) (defining requirements of impairments).

53. 29 C.F.R. pt. 1630, app. § 1630.2(i) (2007) (defining "major life activities" for purposes of discerning whether condition constitutes disability under ADA).

54. *Id.* (providing examples of major life activities). The EEOC has stated that its list is not intended to be exhaustive; sitting, standing, lifting, and reaching are also considered "major life activities." See *id.*

55. See H.R. REP. NO. 101-485, pt. 2, at 52 (providing examples of activities that constitute major life activities under ADA); see also *Bragdon v. Abbott*, 524 U.S. 624, 638 (1998) (holding that "[r]eproduction falls well within the phrase 'major life activity'").

56. See 29 C.F.R. pt. 1630, app. § 1630.2(j) (describing assessment of whether impairment is substantially limiting). The EEOC regulations list the following factors for assessing substantiality of an impairment: "(1) the nature and severity of the impairment, (2) the duration or expected duration of the impairment, and (3) the permanent or long term impact, or the expected permanent or long term impact of, or resulting from, the impairment." See *id.*

57. See generally HUNTINGTON'S DISEASE ASS'N, *supra* note 1 (explaining causes and effects of Huntington's disease).

58. See 29 C.F.R. pt. 1630, app. § 1630.2(j) (explaining that individuals whose daily activities have not yet been affected by disease cannot be considered disabled under ADA). This classification causes some impairments to be disabling for particular individuals but not for others—depending on the stage of the disease or disorder, the presence of other impairments that combine to make the impair-

C. *Asymptomatic, Late-Onset Genetic Disease*

It is not clear from the plain language of the ADA whether the statute covers individuals who have latent genetic defects that will eventually ripen into disabling diseases.⁵⁹ The first prong of the definition of “disability” would not ordinarily apply to asymptomatic individuals.⁶⁰ Generally speaking, such individuals have yet to experience any effects of their condition.⁶¹

Asymptomatic individuals, however, who have genetic defects, may pass them to one or more of their children. It appears, therefore, that the ability of these individuals to procreate and to have intimate sexual relationships—both recognized as major life activities—may be substantially limited.⁶² Affected individuals, therefore, may fall within the ADA’s first prong definition of “disability,” and thus be afforded the ADA’s protection from discrimination. The suggestion that the ADA covers asymptomatic individuals with genetic defects is also present in the Supreme Court’s reasoning in *Bragdon v. Abbott*.⁶³

The third prong of the definition of “disability”—being regarded as having an impairment that substantially limits a major life activity—appears to apply regardless of a disease’s impact on major life activities.⁶⁴ The EEOC has stated that the “regarded as” disability prong covers an individual who:

(1) [h]as a physical or mental impairment that does not substantially limit major life activities but is treated by a covered entity as constituting such limitation;

ment disabling, or any number of other factors. *See id.* Other impairments, however, such as HIV infection, are inherently substantially limiting. *See id.*

59. *See* Rothstein, *supra* note 26, at 42 (describing genetic diseases, some of which would be considered disabilities under ADA and some of which would not).

60. *See* 29 C.F.R. pt. 1630, app. § 1630.2(h) (explaining that disabled individuals are those who experience symptoms due to impairments).

61. *See id.* (distinguishing impairments from environmental and economic factors, which do not constitute impairments under ADA).

62. *See* *Bragdon v. Abbott*, 524 U.S. 624, 638 (1998) (holding that reproduction is major life activity); H.R. REP. NO. 101-485, pt. 2, at 52 (providing examples of activities, including participation in intimate sexual relationships, that constitute major life activities under ADA); *see also* Gin, *supra* note 29, at 1427 (explaining how Huntington’s chorea disease, like HIV, often prevents sufferers from procreating).

63. *See* *Bragdon*, 524 U.S. at 638. The Court stated: “Reproduction and the sexual dynamics surrounding it are central to the life process itself. . . . Our evaluation of the medical evidence leads us to conclude that respondent’s [HIV] infection substantially limited her ability to reproduce.” *Id.* at 638-39 (noting role of reproduction as major life activity).

64. *See* 29 C.F.R. pt. 1630, app. § 1630.2(l) (explaining that ADA’s “regarded as” definition of “disability” is available to individuals whose impairments or diseases do not meet other two statutory possibilities).

(2) [h]as a physical or mental impairment that substantially limits major life activities only as a result of the attitudes of others toward such impairment; or

(3) [h]as none of the impairments defined [by the regulations as per se impairments] but is treated by a covered entity as having a substantially limiting impairment.⁶⁵

The EEOC regulation, unfortunately, does not specifically cover asymptomatic disease-carrying individuals.⁶⁶

The EEOC has attempted to remedy this gap in coverage by issuing supplemental guidance that states that the third prong of the definition of "disability" applies to individuals who are discriminated against on the basis of genetic information relating to illness, disease, or other disorders.⁶⁷ Courts, however, do not always accept the EEOC's interpretation of the ADA.⁶⁸ In *Sutton v. United Air Lines, Inc.*,⁶⁹ the Supreme Court limited the application of the "regarded as" prong to include just two situations: when "(1) a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or (2) a covered entity mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities."⁷⁰ Likewise, some lower federal courts have rejected the EEOC's expansive definition of "regarded as."⁷¹ This dichotomy between the EEOC and judicial interpreta-

65. 29 C.F.R. § 1630.2(1) (2008) (explaining how individuals may be "regarded as" having disabilities under ADA).

66. *See id.* (omitting specific mention of asymptomatic carriers of genetic diseases); Deyerle, *supra* note 21, at 574 (explaining limited scope of "regarded as" definition of disability and difficulty facing potentially disabled, but asymptomatic, individuals).

67. *See* U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, *supra* note 43, § 902.8 (explaining congressional intent that ADA protects even asymptomatic individuals when such individuals are subjects of discrimination).

68. *See, e.g.*, *Ellison v. Software Spectrum, Inc.*, 85 F.3d 187, 189 (5th Cir. 1996) (holding that employee who was treated for breast cancer was not disabled under ADA); *see also* Richard H. Underwood & Ronald G. Cadle, *Genetics, Genetic Testing, and the Specter of Discrimination: A Discussion Using Hypothetical Cases*, 85 Ky. L.J. 665, 678 (1996) (explaining that "[t]he EEOC view may not be accepted by some courts").

69. 527 U.S. 471 (1999).

70. *Id.* at 489 (noting that misperceptions of impairment often result from stereotypes and not from actual capabilities). The 110th Congress reversed the holdings of *Sutton* and other decisions that had limited the scope of the ADA by passing the ADA Restoration Act of 2007. *See* ADA Amendments Act of 2008 § 2(a), Pub. L. No. 110-325, 122 Stat. 3553 (to be codified in scattered sections of 42 U.S.C.).

71. *See* Deyerle, *supra* note 21, at 572. According to Deyerle, "[B]y analogizing to the HIV case law the expansive definition of disability could easily be found by the courts to encompass latent genetic conditions or predispositions to disease. Whether the courts will accept such an expanded definition of disability as reflecting [c]ongressional intent is yet to be determined." *Id.*

tion of the ADA leaves in doubt the outcome of potential cases involving discrimination against asymptomatic individuals with genetic defects.

D. *Asymptomatic Genetic Predisposition to Disease*

If individuals with genetic defects are not destined to develop debilitating illnesses, but merely have increased risks of becoming ill, are they disabled under the ADA?⁷² The same arguments that can be made for individuals with genetic disorders who are asymptomatic can also be made for individuals who are only predisposed to contract certain diseases.⁷³ An individual's ability to engage in reproductive activity may be substantially limited if the genetic defects he or she carries can be inherited.⁷⁴ In such circumstances, the first prong of the ADA's definition of "disability" may apply.⁷⁵ In addition, individuals who are predisposed to contract genetically based diseases may be regarded as having impairments that substantially limit major life activities and, therefore, fall within the third prong of the ADA's "disability" definition. This final possibility will only be available, however, if courts adopt the expanded view of discrimination based upon genetic information now promulgated by the EEOC.⁷⁶

Nevertheless, the applicability of the "regarded as" prong of the ADA's definition of "disability" to individuals who are predisposed to genetically related diseases is tenuous.⁷⁷ The key factor in applying the "regarded as" definition of "disability" is employer perception.⁷⁸ This, in

72. See Rothstein, *supra* note 26, at 45-46 (observing uncertainty of scope of ADA). Rothstein noted: "Although many of the recent discoveries in genetics have involved identifying the loci of genes for single gene disorders, future advances will include discovering the genetic factors that predispose individuals to multifactorial diseases." *Id.* at 45 (noting large potential impact of genetic testing on determining individuals' risk of contracting disorders). The development of some diseases, such as certain forms of cancer and cardiovascular disease, are dependent on exposure to environmental factors. See *id.*

73. For a discussion of how asymptomatic individuals could potentially have disabilities under the terms of the ADA, see *supra* notes 59-71 and accompanying text.

74. See 29 C.F.R. pt. 1630, app. § 1630.2(j) (2007) ("The determination of whether an individual has a disability is not necessarily based on the name or diagnosis of the impairment the person has, but rather on the effect of that impairment on the life of the individual.").

75. See *id.* (providing factors to be used to determine whether impairment is substantially limiting).

76. See U.S. EQUAL EMPLOYMENT OPPORTUNITY COMM'N, *supra* note 43, § 902.8 (addressing issue of asymptomatic individuals facing discrimination). The example that the EEOC used to demonstrate its expansion of "regarded as" to individuals who are subject to discrimination on the basis of genetic information involves an asymptomatic person whose genetic profile reveals an increased susceptibility to colon cancer. See *id.*

77. See 29 C.F.R. pt. 1630, app. § 1630.2(l) (providing examples of when individuals satisfy "regarded as" prong).

78. See *id.* ("[I]f an individual can show that an employer or other covered entity made an employment decision because of a perception of disability based on

turn, is a question of intent.⁷⁹ Unless employees or job applicants can prove that their employers believed that they suffered from a substantially limiting impairment, the employees or applicants will not prevail under the "regarded as" prong.⁸⁰ Proving employers' considerations could be difficult, if not impossible, in situations where employees or applicants have only the potential to develop certain diseases.⁸¹ For individuals with genetic disorders, however, whether a disease is inevitable or merely a higher-than-normal likelihood is irrelevant if they suffer discrimination.⁸²

E. *Unaffected Carriers of Genetic Disorders*

As discussed above, the applicability of the ADA to individuals who are merely genetically predisposed to diseases is questionable.⁸³ The statute's applicability to those who only carry genetic disorders is even more in doubt. In these situations, carriers themselves will be unaffected by the genetic maladies but may transmit them to their offspring.

Although the same arguments used to support the position that the ADA already protects individuals with asymptomatic genetic disorders can also be employed on behalf of unaffected carriers, they are even weaker when applied to this scenario.⁸⁴ For example, the argument that unaffected carriers' abilities to reproduce are substantially limited depends on

'myth, fear, or stereotype,' the individual will satisfy the 'regarded as' part of the definition of disability.')

79. See *Francis v. City of Meriden*, 129 F.3d 281, 284 (2d Cir. 1997) (explaining that "regarded as" definition of disability "turns on the employer's perception of the employee, . . . not whether the employee has a disability").

80. See *id.* at 286 (distinguishing between employers' belief that particular employees are disabled and employers' belief that employees suffer from statutory impairment); see also *Davidson v. Midelfort Clinic, Ltd.*, 133 F.3d 499, 510-11 (7th Cir. 1998) (noting that no evidence supported contention that employer believed employee suffered from substantially limiting impairment). In *Davidson*, the Seventh Circuit held that an employee with Adult Residual Attention Deficit Hyperactivity Disorder was not "regarded as" being disabled by her employer because she was not able to show that the employer perceived her to be substantially limited in her ability to perform a class or range of jobs. See *id.* at 511 ("[T]he most that one can infer from the record is that [the employer] considered [the employee] unable to perform one job for one employer.').

81. See, e.g., *EEOC v. Rockwell Int'l Corp.*, 243 F.3d 1012, 1018 (7th Cir. 2001) (holding that testing for predisposition to disease does not necessarily indicate that employer is misperceiving current impairment).

82. See Brian M. Holt, Comment, *Genetically Defective: The Judicial Interpretation of the Americans With Disabilities Act Fails to Protect Against Genetic Discrimination in the Workplace*, 35 J. MARSHALL L. REV. 457, 464 (2002) (noting that language of ADA does not clearly state whether Congress intended that statute protect individuals predisposed to developing diseases in future).

83. For a discussion of the ADA's ambiguity regarding its protections of individuals who are predisposed to genetic diseases, see *supra* notes 72-82 and accompanying text.

84. For a summary of the arguments that suggest that the protections of the ADA apply to individuals with asymptomatic genetic disorders, see *supra* notes 59-82 and accompanying text.

various factors—including whether the mode of inheritance is dominant, recessive, or X-linked, the nature of the disorders in question, and the age of onset.⁸⁵ The argument that employers regard applicants or employees as having impairments that substantially limit major life activities implies a sophisticated knowledge of genetics on the part of the employers.⁸⁶

An additional problem under the third prong, or “regarded as” definition, is that unaffected carriers are just that—unaffected. It would be extremely difficult for unaffected carriers to prove that their employers treated them like individuals who have impairments that substantially limit major life activities. Employers’ best defense to discrimination claims would be to acknowledge the truth, i.e., that unaffected carriers are not and never will be substantially limited as a result of genetic mutations that they carry.⁸⁷

Whether the ADA protects unaffected carriers of genetic disorders is far from certain. Although several arguments to support coverage could be made, nothing in the statute or the regulations clearly dictates an affirmative answer to the question. It was to remedy the resulting potential gap in coverage that Congress passed the Genetic Information Nondiscrimination Act of 2008.⁸⁸

85. See Rothstein, *supra* note 26, at 49 (explaining that some asymptomatic carriers of genetic diseases may or may not fall within ADA’s definition of disability). For example, a parent who carries a predisposition to a genetic disorder in a recessive gene is only twenty-five percent likely to produce offspring affected by the disorder. See *id.* at 45 (discussing potential risk of developing genetic diseases).

86. See *id.* at 48 (noting that employers’ knowledge of genetics affects arguments for including carriers of genetic diseases within ADA’s protections).

87. See *id.* at 49-50 (“A sophisticated employer who knew that a carrier of a recessive or X-linked disorder is not at risk would not regard the carrier as having an impairment.”). Rothstein has proposed a third theory by which an unaffected carrier is covered under the ADA: an employer would be guilty of discrimination under Section 12112(b)(4) if that employer excluded or otherwise denied equal jobs or benefits to an unaffected carrier because such individual has a relationship or associates with a person who has a known disability—to wit, the symptomatic child of the carrier. See *id.*

88. See Jennifer Chorpeneing, *Genetic Disability: A Modest Proposal to Modify the ADA to Protect Against Some Forms of Genetic Discrimination*, 82 N.C. L. REV. 1441, 1475 (2004) (recommending certain amendments to ADA). Chorpeneing proposed amending the ADA so that it stops discrimination against individuals who are asymptomatic but predisposed to diseases protected under the statute. See *id.* at 1475. She would also have the ADA allow employers to refuse to hire asymptomatic individuals whose diseases would constitute a direct threat to themselves or others. See *id.* at 1476 (advocating clear exception for employers’ refusal to hire in certain circumstances).

Other commentators have argued that the best way to protect individuals with genetic predispositions from employment discrimination is to amend Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e to 2000e-17 (2006). See, e.g., Holt, *supra* note 82, at 479-80 (“Amending Title VII would enable applicants who have been rejected based on their genetic predispositions to establish a prima facie case of unlawful discrimination.”). Still others have proposed that the solution can be found in a new statute that would prohibit use of genetic information in hiring, firing, and terms and conditions of employment, but still allow employers to refuse

V. OVERVIEW OF TITLE II OF THE GENETIC INFORMATION NONDISCRIMINATION ACT

Despite Congress's apparent intent to have the ADA prohibit discrimination based upon genetic defects or disorders, a careful analysis of the statute leaves great uncertainty as to whether the courts would so apply it. Indeed, the Supreme Court limited the application of the "regarded as" prong of the definition of "disability," which is a key argument in applying the ADA to some stages of genetic defects.⁸⁹ In addition, other courts have failed to find unlawful discrimination even when medical tests reveal susceptibility to medical problems.⁹⁰ Congress passed GINA to address these deficiencies and to fill the resultant gap in coverage.

A. *Prohibited Practices*

The bill that became the Genetic Information Nondiscrimination Act of 2008 was first introduced to the House of Representatives by Representative Louise M. Slaughter (D., N.Y.) in 1995.⁹¹ After thirteen years of torturous wrangling, Congress finally produced a law that clearly and unequivocally prohibits discrimination based upon individuals' genetic traits not only in the area of access to health insurance, but also in the realm of employment.⁹² Congress noted the reported problems of genetic discrimination in the workplace, such as the use of genetic testing to screen out workers with sickle cell trait.⁹³ Congress also found "the existing patch-

to hire or to fire in order to maintain a safe workplace. *See, e.g.*, Jared A. Feldman & Richard J. Katz, Note, *Genetic Testing & Discrimination in Employment: Recommending a Uniform Statutory Approach*, 19 HOFSTRA LAB. & EMP. L.J. 389, 424-27 (2002) (providing model statute to achieve balance between protection of employees and flexibility for employers).

89. *See* Sutton v. United Air Lines, Inc., 527 U.S. 471, 489 (1999) (holding that "regarded as" prong of ADA's definition of disability only applies when covered entities believe that individuals are substantially limited in one or more life activity).

90. *See* EEOC v. Rockwell Int'l. Corp., 243 F.3d 1012, 1017 (7th Cir. 2001) (finding for defendants when plaintiffs could not prove that their employer considered them to be substantially limited).

91. *See* Editorial, *Genetic Discrimination—Fundamental Rights*, PHILA. INQUIRER, May 3, 2008, at A8 (discussing history of bill that became GINA).

92. *See* Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (2008) (to be codified at 42 U.S.C. §§ 2000ff to 2000ff-11), at pmb1. (declaring that GINA's purpose is "to prohibit discrimination on the basis of genetic information with respect to health insurance and employment").

93. *See id.* § 2(4) (citing facts of Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998), as one of many reasons to pass statute). In *Norman-Bloodsaw*, workers at a laboratory operated by federal and state agencies alleged that they had been tested by their employers for several medical conditions without the workers' knowledge or consent. *See* 135 F.3d at 1264. The Ninth Circuit found for the defendants in the workers' claim under the ADA. *See id.*

work of state and federal laws to be confusing and inadequate to protect [the public] from discrimination.”⁹⁴

Title II of GINA contains provisions that prohibit discrimination based upon genetic information in employment.⁹⁵ These provisions apply to employers, and their employees, who meet the requirements found in other federal laws.⁹⁶ The statute further extends obligations to employment agencies, unions, and other labor organizations.⁹⁷

GINA has several basic tenets. First, it is unlawful for employers to discriminate against employees in terms of hiring, promotion, firing, or any other terms and conditions of employment.⁹⁸ Secondly, it is also unlawful for employers to negatively limit, segregate, or classify employees because of genetic information.⁹⁹ Finally, it is unlawful for employers to request, require, or purchase genetic information about employees or employees’ family members, with limited exceptions.¹⁰⁰ These prohibitions apply not only to employers, but also to employment agencies and labor organizations.¹⁰¹ Employers, labor organizations, and joint labor-management committees that are involved in training programs are also covered.¹⁰²

In order to understand the rights and duties created by GINA, one must understand the concept of “genetic information.” Individuals can now undergo genetic tests whereby their DNA, ribonucleic acid (RNA), or

94. Genetic Information Nondiscrimination Act § 2(5) (explaining developments in science and law that contributed to Congress’s passing GINA).

95. *See id.* § 202 (detailing employment practices made unlawful by GINA). On March 2, 2009, the EEOC issued proposed regulations explaining its interpretations of GINA. *See* Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9056 (proposed Mar. 2, 2009) (to be codified at 29 C.F.R. pt. 1635). In these proposed regulations, the EEOC noted Congress’s “intent to prohibit discrimination with respect to a wide range of covered entity practices, including hiring, promotion and demotion, seniority, discipline, termination, compensation, and the terms, conditions, and privileges of employment,” and attempted to interpret all of Title II’s prohibitions in light of this intent. *Id.* at 9060.

96. *See* Genetic Information Nondiscrimination Act § 201(2)(A), (B) (identifying as subject employers those with fifteen or more employees, those that form part of state or local governments, and certain federal government entities).

97. *See id.* § 201(2)(C).

98. *See id.* § 202(a) (describing circumstances in which discrimination based on genetic information against employees is prohibited).

99. *See id.*

100. *Id.* § 202(b) (listing actions employers are prohibited from taking in relation to employees’ and their families’ genetic information).

101. *See id.* §§ 203-04 (banning discrimination based on genetic information and acquisitions of this information by employment agencies and labor organizations).

102. *See id.* § 205 (extending prohibitions on discrimination based upon genetic information to employers, labor organizations, or joint labor management committees that control training programs).

chromosomes may be analyzed.¹⁰³ These tests are designed to detect genotypes, mutations, and chromosomal changes in the subject individuals.¹⁰⁴ The information that is derived from these genetic tests is the genetic information that employers are prohibited from using in making employment decisions about employees. For example, if an analysis of an employee's chromosomes revealed that the employee had a defect associated with Huntington's disease, then an employer would not be permitted to use this information in making employment decisions.

GINA prohibits employers from requesting, requiring, or purchasing genetic information about employees or employees' family members.¹⁰⁵ There are five exceptions to this rule. First, employers may acquire genetic information if the information is acquired as a result of an inadvertent request or requirement of family medical histories.¹⁰⁶ In light of the prohibition under the ADA of requesting medical information before making offers of employment, this scenario is most likely to arise after employees begin their jobs.¹⁰⁷

The second exception to the rule against obtaining employees' genetic information allows employers to acquire information as a result of their offers of health or genetic services to employees, particularly if the information is part of bona fide wellness programs.¹⁰⁸ In this situation, employees must knowingly and voluntarily provide written authorization before engaging in such services.¹⁰⁹ Individually identifiable information about the results may only be shared with the subject employees or family members and the licensed health care professionals or board certified ge-

103. *See id.* § 201(7)(A) (defining "genetic test" as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes"). Misuse of genetic information derived from such tests was one of the findings Congress used to justify passage of GINA. *See id.* § 2(1).

104. *See id.* § 201(7)(A) (defining "genetic test"). Tests that analyze proteins or metabolites but that do not detect genotypes, mutations, or chromosomal changes are not included in the definition of "genetic test." *See id.* § 201(7)(B) (excepting these tests from definition of "genetic test" under GINA).

105. *See id.* § 202(b) (declaring it unlawful for employers to acquire genetic information except under certain circumstances).

106. *See id.* § 202(b)(1) (excepting unintentional requests for medical history from statute's general prohibition).

107. *See* 42 U.S.C. § 12112(d)(2)(A) (2006) (prohibiting pre-employment medical exams aimed to determine "whether [an] applicant is an individual with a disability or . . . the nature or severity of such disability").

108. *See* Genetic Information Nondiscrimination Act § 202(b)(2)(A) (excepting acquisition of genetic information for wellness program from statute's general prohibition).

109. *See id.* § 202(b)(2)(B) (requiring that employees provide "prior, knowing, voluntary and written authorization" before employers may obtain their genetic information under GINA's statutory exceptions).

netic counselors who provide the testing services.¹¹⁰ Employers are only entitled to information derived from the services in aggregate terms that do not disclose the identity of particular subject-employees.¹¹¹

A third exception involves state and federal medical leave laws. Employers may request family medical histories in order to comply with certification provisions of the Family and Medical Leave Act and similar state laws.¹¹² Fourth, employers may purchase commercially and publicly available documents that contain family medical histories of employees.¹¹³

The final exception under which employers are entitled to obtain genetic information regarding employees or family members involves genetic monitoring.¹¹⁴ GINA defines “genetic monitoring” as the “periodic examination of employees [in order] to evaluate acquired modifications to their genetic material.”¹¹⁵ Since these modifications may have developed in the course of employment due to exposure of toxic substances in the workplace, such monitoring is necessary to evaluate and respond to their effects and causes.

Despite allowing for employers’ gathering of genetic information in these circumstances, GINA places many restrictions on such activity. First, employers must provide employees with written notice of genetic monitoring.¹¹⁶ Second, employees must provide written, knowing, and voluntary authorization to such monitoring before it begins, unless the monitoring is required by federal or state law.¹¹⁷ Third, employers must inform their employees of individual monitoring results.¹¹⁸ Fourth, genetic monitoring must comply with any federal or state genetic monitoring regulations.¹¹⁹ Finally, employers are entitled to receive only the results of genetic monitoring in the aggregate so that acquired information does not disclose the identity of any individual employees.¹²⁰

110. *See id.* § 202(b)(2)(C) (limiting “individually identifiable information concerning the results” of genetic tests to employees and health care professionals).

111. *See id.* § 202(b)(2)(D) (preventing disclosure of employees’ identities in conjunction with their genetic information).

112. *See id.* § 202(b)(3) (citing Family Medical Leave Act of 1993 § 103, 29 U.S.C. § 2613 (2006)).

113. *See id.* § 202(b)(4) (allowing acquisition of genetic information from sources “including newspapers, magazines, periodicals and books, but not including medical databases or court records”).

114. *See id.* § 202(b)(5) (legalizing, under certain conditions, gathering of genetic information “where the information involved is to be used for genetic monitoring of the biological effects of toxic substances in the workplace”).

115. *Id.* § 201(5).

116. *See id.* § 202(b)(5)(A) (requiring written notice for genetic monitoring).

117. *See id.* § 202(b)(5)(B) (establishing need for “prior, knowing, voluntary and written authorization” from employees).

118. *See id.* § 202(b)(5)(C) (requiring release of information to employees).

119. *See id.* § 202(b)(5)(D) (mandating that genetic monitoring be in accordance with federal or state laws).

120. *See id.* § 202(b)(5)(E) (limiting results employers can receive from genetic monitoring to aggregate). A final exception deals with DNA analysis for law

B. Confidentiality

In addition to proscribing various practices, GINA seeks to maintain the confidentiality of genetic information of employees that comes into the possession of employers, employment agencies, labor organizations, or joint labor-management committees. In short, this information must be maintained on separate forms and in separate medical files and be treated as confidential medical records of individual employees or labor organization members.¹²¹ Genetic information, however, may be disclosed to subject employees, at their written request; to government officials investigating compliance with the statute; to occupational or other health researchers; in response to court orders; or in order to comply with provisions of the Family and Medical Leave Act.¹²²

C. Remedies and Enforcement

GINA follows existing legislation in its remedies and enforcement provisions. In general, the EEOC and the Attorney General have the same powers, remedies, and procedures that exist under the Civil Rights Act of 1964.¹²³ These powers include the ability to file and investigate a charge of discrimination and to bring a civil action against the employer, employment agency, labor organization, or joint labor-management committee.¹²⁴ Remedies include hiring, reinstatement, promotion, back pay, and injunctive relief.¹²⁵ If an employee is a prevailing party, a court may award attorney's fees, including expert fees and costs.¹²⁶ Finally, aggrieved employees may also recover compensatory and punitive damages up to \$300,000.¹²⁷ GINA mirrors corresponding laws that prohibit discrimination against covered federal employees and certain state employees.¹²⁸

enforcement purposes. *See id.* § 202(b)(6) (authorizing genetic monitoring "where the employer conducts DNA analysis for law enforcement purposes as a forensic laboratory or for purposes of human remains identification, and requests or requires genetic information of such employer's employees").

121. *See id.* § 206(a) (detailing storage of genetic information).

122. *See id.* § 206(b)(5) (noting that release of information may be required by Family Medical Leave Act § 103).

123. *See id.* § 207(a) (incorporating powers and remedies in Civil Rights Act of 1964, 42 U.S.C. §§ 2000e-4 to e-6 (2006)).

124. *See* 42 U.S.C. § 2000e-5 to -6 (2006) (listing powers available to EEOC and Attorney General in investigating and attempting to remedy purported instances of discrimination).

125. *See id.* § 2000e-5(g) (listing remedies available for unlawful employment practices).

126. *See* Genetic Information Nondiscrimination Act § 207(a)(2) (citing 42 U.S.C. § 1988 (2006)) (authorizing courts to impose fees to be paid to prevailing parties).

127. *See id.* § 207(a)(3) (citing 42 U.S.C. § 1981a (2006)).

128. *See id.* § 207(b) (citing Government Employee Rights Act of 1991, 42 U.S.C. § 2000e-16b to 16c) (banning discrimination for individuals appointed by state officials); *id.* § 207(c) (citing Congressional Accountability Act of 1995, 2 U.S.C. §§ 1301-1438 (2006)) (banning discrimination for employees of United

D. Miscellaneous Provisions

Two miscellaneous provisions complete GINA and have bearing on its understanding. First, the statute does not recognize a cause of action for “disparate impact.” While it is illegal for employers to discriminate in a blatant and intentional way based upon employees’ genetic information, GINA does not prohibit employers from having job qualifications that, although neutral on their face, are not job-related and have a disproportionate impact on members of a protected class.¹²⁹

For example, an employer could have a policy of only hiring persons with blue eyes. Although the policy would have a disparate impact on persons who do not possess the gene for blue eyes, it would not be grounds for a discrimination action under GINA. Being sensitive to where science may be going on this issue, GINA requires the establishment of a commission, known as the Genetic Nondiscrimination Study Commission, six years after the statute’s effective date. The Commission will study the developing science of genetics and make recommendations regarding whether GINA should contain disparate impact as a cause of action.¹³⁰

The other notable provision relates to medical information that is not also genetic information. GINA clarifies that employers do *not* violate the statute by using, acquiring, or disclosing medical information that is not genetic information relating to a disease, disorder, or pathological condition, even where the information may have a genetic basis.¹³¹ In other words, if the genetic information that comes into the possession or is used by employers is not related to some pathological condition—for example, a genetic predisposition to have prematurely gray hair—then no violation has occurred.

VI. COMPROMISES UNDER GINA

Like most pieces of legislation, GINA contains a series of compromises that were necessary in order to ensure its passage. First, it appears that Congress compromised in defining a theory under which aggrieved employees can bring private suits under the statute. Under the

States House of Representatives and United States Senate); *id.* § 207(d) (citing 3 U.S.C. § 411(a)(1) (2006)) (banning discrimination for certain employees of Executive branch); *id.* § 207(e) (citing Civil Rights Act of 1964, 42 U.S.C. § 2000e-16 (2006)) (banning discrimination for federal employees in Executive and Judicial Branches and other units).

129. *See* Genetic Information Nondiscrimination Act § 208(a) (explaining that “disparate impact” as defined by Civil Rights Act of 1964, 42 U.S.C. § 2000e-2(k) (2006), “does not establish a cause of action under [GINA]”).

130. *See id.* § 208(b) (establishing Genetic Nondiscrimination Study Commission to determine if disparate impact should be cause of action under GINA in future).

131. *See id.* § 210 (requiring misuse of “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” for cause of action).

Civil Rights Act of 1964 and similar employment discrimination laws, employees can not only bring suit if they were blatantly discriminated against because they are members of a protected class—i.e., disparate treatment—but also if job qualifications, though neutral on their face, impact a protected class disproportionately—i.e., disparate impact.¹³² GINA, however, specifically bars lawsuits brought based upon a theory of disparate impact.¹³³

Instead, Congress provides that the Genetic Nondiscrimination Study Commission is to be formed in six years in order “to review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act.”¹³⁴ Congress is clearly concerned about how the science of genetics will develop over time and how developments may impact public policy that attempts to balance both employees’ right to be free from discrimination and employers’ right to hire the best qualified people for available jobs.

In drafting GINA, Congress also compromised its main goal of protecting employees from genetic discrimination by allowing employers to acquire this information in certain circumstances. Generally, GINA prohibits employers from requesting, requiring, or purchasing genetic information regarding employees or their families.¹³⁵ Despite this clear prohibition, however, the statute describes several circumstances under which employers can receive this information. For example, they may do so when acquisition is the result of inadvertent requests, wellness programs, scenarios involving the Family and Medical Leave Act, criminal investigations, or when the information is publicly available.¹³⁶ Even in these situations, however, GINA prohibits employers from using legally acquired information to discriminate.¹³⁷

Finally, exceptions to GINA’s provisions related to confidentiality temper the statute’s generally harsh language. In most situations, GINA prohibits employers from disclosing employees’ genetic information, re-

132. See 42 U.S.C. § 2000e-2(a)-(c) (2006) (defining discriminatory practices under Civil Rights Act); see also § 2000e-2(k) (further defining disparate impact and required proof); *Griggs v. Duke Power Co.*, 401 U.S. 424, 431 (1971) (“The Act proscribes not only overt discrimination but also practices that are fair in form, but discriminatory in operation.”).

133. See Genetic Information Nondiscrimination Act § 208 (leaving issue of whether “disparate impact” should be cause of action under GINA to be determined by Commission in six years).

134. *Id.* § 208(b) (describing planned formation of Genetic Nondiscrimination Study Commission and its duties).

135. See *id.* § 202(b) (banning acquisition of genetic information except under certain circumstances).

136. See *id.* (listing exceptions for acquisition of genetic information).

137. See *id.* § 202(c) (preventing legally obtained genetic information from being used to discriminate).

ardless of how that information is acquired.¹³⁸ This prohibition, however, is modified in circumstances where the request comes from the employees themselves or the employees' family members, from occupational or other health researchers, from government compliance officials, from court orders, or in connection with the Family and Medical Leave Act.¹³⁹ Most importantly, employees' genetic information may be disclosed without their consent if the information concerns the manifestation of contagious diseases that involve death or life-threatening illness.¹⁴⁰ Clearly, in drafting GINA, Congress considered potential threats to public health to be higher priorities than personal privacy concerns.

VII. CONCLUSION

The new millennium has brought with it an amazing new world of science and technology. Perhaps no recent scientific discovery, however, will be more important to the average person than that which will unlock the door to increasing knowledge of life itself—genetics. Through the Human Genome Project, scientists and doctors will possess an unprecedented ability to identify, and in some cases rectify, defects in human beings' individual genomes.¹⁴¹

With the ability to identify genetic defects, however, comes the danger that such information may be used to categorize or discriminate against individuals. Employers who gain access to the genetic information of job applicants or current employees have the power to base employment decisions upon the probability that the applicants or employees will develop disabling genetic diseases.¹⁴² Concerned about productivity and insurance costs, employers would be tempted to employ only those qualified individuals who possess the most "normal" genetic codes.

The Americans with Disabilities Act was passed to end discrimination against individuals with disabilities.¹⁴³ The legislative history of the ADA reveals a settled purpose in the employment field: to give a qualified indi-

138. *See id.* § 206(b) ("An employer, employment agency, labor organization, or joint labor management committee shall not disclose genetic information concerning an employee or member.").

139. *See id.* § 206(b)(1)-(5) (listing circumstances in which disclosure of genetic information is permitted).

140. *See id.* § 206(b)(6) (allowing disclosure of "a contagious disease that presents an imminent hazard of death or life threatening illness" to "a Federal, State, or local public health agency" if affected employees are also notified of disclosure).

141. *See* National Human Genome Research Institute, *supra* note 19 (defining genome and discussing impact of mapping entire human genome). For a discussion of genes, chromosomes, and the human genome, as they relate to the Genetic Information Nondiscrimination Act, see *supra* notes 14-21 and accompanying text.

142. For an account of how employers can use genetic information to discriminate against employees, see *supra* notes 22-30 and accompanying text.

143. For analysis concerning Congress's intent that the protections of the ADA apply to individuals with genetic defects, see *supra* notes 31-43 and accompanying text.

vidual a fair chance to secure a meaningful job regardless of the individual's disability, as long as the individual can perform the essential functions of the job. Despite the legislative history, the ADA itself and the substantive regulations promulgated under the ADA by the EEOC leave serious doubt as to whether the statute matches congressional intent when it is applied to individuals with genetic defects.¹⁴⁴ Although the ADA clearly applies to individuals with abnormal genetic traits and symptomatic genetic diseases, it is uncertain whether asymptomatic individuals who have or will have increased risks of contracting a genetic disease, or those who merely carry genetic defects, meet the definition of disability under the ADA.

In order to remedy this gap in protection, Congress passed the Genetic Information Nondiscrimination Act.¹⁴⁵ GINA protects from discrimination individuals who have a genetic predisposition to contract or to transmit by heredity impairments that substantially limit major life activities. In addition, GINA broadly defines "genetic information" in order to encompass all aspects of individuals' genotypes.

Congress enacted the Americans with Disabilities Act "to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals."¹⁴⁶ Unfortunately, science surpassed the provisions of that statute. Employers gained the ability to discriminate against qualified individuals on the basis of their genetic information, at least until they actually developed or passed on a debilitating genetic disease. Clearly, in order to close this gap in coverage under the ADA, Congress used GINA to further its original intent of eliminating discrimination against *all* disabled individuals—including those whose disabilities are not easily perceived. Though only the passage of time and future court decisions will reveal how well this new legislation meets this goal, one hopes that justice for individuals based upon their genetic code has finally been achieved. Sarah can now undergo the genetic test for Huntington's disease, free from fear that it could cost her her job and livelihood.

144. For a discussion of the ADA's inability to extend to several possible scenarios of genetic discrimination, see *supra* notes 44-88 and accompanying text.

145. For a comprehensive overview of GINA, including a discussion of the goals pursued, and compromises made, by Congress through passage of the statute, see *supra* notes 89-140 and accompanying text.

146. 42 U.S.C. § 12101(b)(2) (2006) (defining purposes of Americans with Disabilities Act).

