

LEGAL AND ETHICAL CONSIDERATIONS IN GENETIC TESTING IN THE WORKPLACE

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“We used to think our fate is in our stars. Now we know, in large measure, our fate is in our genes.”¹

--James D. Watson, DNA co-discoverer

I. INTRODUCTION

The blueprint for building and operating a fully functional human being is contained within the genetic code, deoxyribonucleic acid, which is abbreviated as DNA.² DNA determines basic physical characteristics such as configuration of limbs and internal organs, as well as traits unique to particular individuals such as body structure, hair and eye color. In addition to determining unique physical factors, recent research shows that many less tangible characteristics have significant heritable components, including general intelligence, aptitudes, personality, interests, and even job satisfaction and overall happiness.³

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¹ Leon Jaroff, *The Gene Hunt*, TIME, Mar. 20, 1989, at 62–67 (quoting James D. Watson).

² The acronym DNA stands for deoxyribonucleic acid, the molecule that encodes the genetic blueprints of all living creatures on earth. See James D. Watson & Francis H. Crick, *Genetical Implications of the Structure of Deoxyribonucleic Acid*, 171 NATURE 964 (1953). See also Frederic Golden & Michael D. Lemonick, *The Men Who Mapped the Genome*, TIME, July 3, 2000, at 18-31.

³ Richard D. Arvey & Thomas J. Bouchard, Jr., *Genetics, Twins, and Organization Behavior*, 16 RES. ORG. BEHAV. 47-82 (1994); Thomas J. Bouchard, Jr., *Genetic Influence on Mental Abilities, Personality, Vocational Interests, and Work Attitudes*, 12 INT’L REV. INDUS. & ORG. PSYCHOL., 373-95 (1997).

During the same week in June 2000 two different teams of scientists declared that they had assembled a rough draft of the entire human genome, some 3.1 billion biochemical “letters” of human DNA. Francis Collins, the director of the National Human Genome Research Institute, and Craig Venter, the Chief Executive Officer of Celera Genomics, joined President Clinton at a press conference to announce their completion of the first map of the human genome. “Today... marks an historic point in the 100,000-year record of humanity,” declared Venter. “Our species can read the chemical letters of its genetic code.” Collins was equally effusive: “Today, we celebrate the revelation of the first draft of the human book of life...We have caught the first glimpse of our own instruction book, previously known only to God.”⁴ With such a simple proclamation, the Century of Physics passed and we entered what may be the Century of Biology.⁵ Indeed, DNA is likely to be the twentieth century discovery that will be most important in the twenty-first.

Armed with genetic code, scientists may now start teasing out the secrets of human health and disease at the molecular level — secrets that will lead, at the very least, to a revolution in diagnosing and treating many kinds of disorders.⁶ More than 5,000 medical conditions have been traced directly to defective genes including: Huntington’s chorea, Alzheimer’s, cystic fibrosis, sickle cell anemia, thalassaemia, muscular dystrophy, Tay-Sachs disease, and bowel cancer.⁷ There are also suspected genetic factors associated with other cancers, heart disease, diabetes, arthritis, dyslexia, and some mental illnesses. In a matter of decades the science of medicine may be transformed by these discoveries.

Historically, changes in science and medicine have prompted changes in law and policy. For example, with each improvement in forensic science, such as blood typing, polygraph testing, and fingerprinting, law and policy governing criminal investigations changed. Given such improvements society demanded more of the criminal justice system. Consequently, rules of criminal procedure became more complex, prosecutions more legitimate, and, convictions more accurate, at least in theory.

New knowledge, along with attendant technology and its use, tend to arouse ethical and legal debate. For example, the ability to sustain an injured or diseased human on life support gave rise to issues concerning euthanasia and the right to die.⁸ The ability to decipher a person’s genetic code begs discourse on the ethical and legal implications of

⁴ William Saletan, *The Human Genome* (2000), at <http://slate.msn.com/code/story> (last visited July 7, 2000). The actual completed sequence of the human genome was published simultaneously by Venter and his associates in *The Sequence of the Human Genome*, SCIENCE, Feb. 16, 2001, at 291 and Collins and The Genome International Sequencing Consortium in *Initial Sequencing and Analysis of the Human Genome*, NATURE 409, Feb. 15, 2001, at 860-921. “The sequencing of the human genome has been likened to landing on the moon, splitting the atom, and even inventing the wheel.” See www.nature.com/nsu/Hgindex.html (last visited February 21, 2001).

⁵ The 20th Century has been called the Century of Physics because of the extraordinary advancements in understanding and harnessing the forces of the atom and the universe. Walter Isaacson, *Who Mattered—and Why?*, TIME, Dec. 31, 1999, at 48-60.

⁶ Lila Guterman, *For Sale: The Book of Life*, CHRON. HIGHER EDUC., Sept. 27, 2000, at A20-22.

⁷ Thomas C. Caskey, *DNA-Based Medicine: Prevention and Therapy*, in CODE OF CODES 112, 116-120. (Daniel J. Devles, & Leroy Hood, eds. 1992); Mike Thatcher, *Contending With a Genetic Timebomb*, 2 PEOPLE MGMT. 30, 30-32 (1996).

⁸ Michael Shapiro, *Is Bioethics Broke?: On the Idea of Ethics and Law “Catching Up” With Technology*, 33 IND. L. REV. 17, 93-94 (1999). The right to die cases center on issues of privacy. See generally, ELLEN ALDERMAN & CAROLINE KENNEDY, THE RIGHT TO PRIVACY 127-39 (1995).

genetic testing and raises many questions: will genetic testing be used for or against society and individuals? what pressures might be brought to disclose results? could disclosing genetic test results encourage discrimination against or selective exclusion of those tested? what rights do individuals have to prevent such assessments or bar disclosure of results from tests performed for unrelated reasons? do employers, colleagues, friends, and/or relatives have a right to know such intimate details about one's life? are laws already in place sufficient to protect individuals or is special legislation required?

This article highlights some of the important questions prompted by genetic testing, addressing selected issues and encouraging further discourse on the unanswered, and perhaps unanswerable questions. Section II outlines genetic testing methods and potential applications within the workplace. Section III discusses ethical and legal implications of genetic testing in employment, with special emphasis on constitutional rights to privacy and equal protection. A review of the relevant current law responsive to issues raised by genetic testing is set forth in Section VI, followed by conclusions.

II. GENETIC TESTING METHODS AND POTENTIAL EMPLOYMENT APPLICATIONS

Stemming in large part from the Human Genome Project (HGP), the ongoing explosion of new knowledge about the structures and functions of human genes and new laboratory technology for analysis of genetic material is yielding a wealth of information about human traits.⁹ Scientists have developed and are continuing to hone multifactor genetic tests to indicate susceptibility to a wide range of disorders.¹⁰ Genetic tests require samples of body tissue, such as hair, fingernails, urine, or blood. With the exception of drawing blood, genetic tests need not be invasive. Genetic tests encompass both identifying individuals with particular inherited traits or tendencies toward disorders (screening) and examining persons for evidence of induced change in their genetic material (monitoring).¹¹

⁹ A generally accepted definition of genetic tests is provided by the TASK FORCE ON GENETIC TESTING, JOHNS HOPKINS UNIVERSITY, FINAL REPORT : PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES 5 (Neil A. Holtzman & Michael S. Watson, eds. 1997), at http://www.nhgri.nih.gov/ELSI/TFGT_final/: "The analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites in order to detect heritable disease-related genotypes, mutations, phenotypes, or karyotypes, for clinical purposes. Such purposes include predicting risk of disease, identifying carriers, and establishing prenatal and clinical diagnosis or prognosis. Prenatal, newborn, and carrier screening, as well as testing in high risk families, are included. Tests for metabolites are covered only when they are undertaken with high probability that an excess or deficiency of the metabolite indicates the presence of heritable mutations in singly genes" [hereinafter Holtzman & Watson].

¹⁰ *Id.* at 30.

¹¹ Kirke D. Weaver, *Genetic Screening and the Right Not to Know*, 13 ISSUES LAW & MED. 243-82 (1997).

A. GENETIC SCREENING

Genetic screening detects specific alleles (mutations) in DNA that indicate certain traits or predispositions toward disease or a genetic condition.¹² Pre-dispositional testing offers unprecedented means to estimate or predict future disease risks for currently healthy individuals and their offspring.¹³ For instance, women with the BRCA1 gene have an 80 percent to 90 percent risk during their lifetimes of developing breast cancer and have a significantly higher than average risk of ovarian cancer.¹⁴ An employer could use predispositional testing as a basis to exclude individuals from employment or benefits because of general defects and conditions unrelated to specific factors relevant to the workplace environment.¹⁵ While employers may have valid reasons to use genetic screening as a method of minimizing overall costs of the workforce, doing so could lead to reduced insurance and disability costs, along with fewer worker absences and maximal productivity.

Arguably, employers also may have interest in knowing potential employees' predisposition for certain behaviors or abilities.¹⁶ For example, for nearly a century employers have been able to give applicants, as well as employees, psychological assessments to discern characteristics such as cognitive ability, mechanical aptitude, sensory-motor skills, job and career interests, personality traits, and whether they have tendencies to lie or steal.¹⁷ Psychological evaluations designed to detect psychopathology or deviant personality types may aid employers in screening potentially troublesome employees.¹⁸ However, as with all such measures, a margin of error exists, meaning results are not proof that any given individual will demonstrate indicated behaviors in the workplace. Methods can predict positive traits also, for example, whether a particular applicant with a targeted personality profile (e.g., extroversion) would be an exceptional salesperson. Thus, psychological tests may be useful only if the person using the results understands the inherent and substantial limitations. Genetic assessment may have similar strengths and weaknesses. The question remains: even if scientists find a genetic marker for certain behavioral characteristics (e.g. aptitudes or personality traits), would employers be able to claim a legitimate use for such information?

¹² Jennifer Jendusa, *Notes and Comments: Pandora's Box Exposed: Untangling The Web of The Double Helix in Light of Insurance and Managed Care*, 49 DEPAUL L. REV. 161 (1999).

¹³ Philip R. Reilly, *Public Policy and Legal Issues Raised by Advances in Genetic Screening and Testing*, 27 SUFFOLK U. L. REV. 1327-35 (1993).

¹⁴ Aimee L. Wonderlick & Beth A. Fine, *Knowledge of Breast Cancer Genetics Among Breast Cancer Patients and First-Degree Relatives of Affected Individuals*, J. GENETIC COUNS., 111, 112-119 (1997); Georgia L. Wiesner, *Clinical Implications of BRCA1 Genetic Testing for Ashkenazi-Jewish Women*, 7 J. L. & MED., 3-11 (1997).

¹⁵ Weaver, *supra* note 11, at 244.

¹⁶ ALDERMAN & KENNEDY, *supra* note 8, at 275-76.

¹⁷ For example, the Multiphasic Personality Inventory (MMPI, developed in the 1940's) and California Personality Inventory (CPI, developed in the 1950's) tests have long been used in the employment context.

¹⁸ ALDERMAN & KENNEDY, *supra* note 8, at 284.

Genetic tests offer more than improved capability for diagnosing existing disease and initiating medical or behavioral procedures.¹⁹ The benefits of some procedures can be substantial, such as screening for those who may be affected by thalassaemia, a deficiency that results in smaller red blood cells, ones adversely affected by exposure to lead or benzene, common workplace chemicals in some industries.²⁰

There are caveats related to genetic testing. First, genetic test results do not necessarily mean that a given affliction will inevitably occur and do not predict the course such disorders may take. Second, given the complexity of many diseases tests have only a limited ability to accurately predict clinical outcome.²¹ Third, for those who may contract a predicted disorder, the age of onset, severity, and unique responses to treatment seldom can be predicted.²² Finally, the validity of genetic test results depends on the skills of those administering and interpreting the procedures.²³ Genetic screening for predispositions may simply supplement or replace risk estimates based on population data and/or family history. Like psychological assessment, genetic screening may be useful if the user of such information recognizes the limitations. Moreover, a red flag must be raised when employers are tempted to reduce operating costs at the possible expense of individual rights.

Genetic screening is used in forensics, through DNA profiling.²⁴ In criminal investigations, DNA evidence obtained at crime scenes (e.g. hair, blood, or semen) is compared to that of a suspect.²⁵ As demonstrated by the defense arguments in the O.J. Simpson trial, an error rate currently attends DNA profiling. Nevertheless, employers could benefit from current DNA profiling technology to help identify possible suspects in work place wrongdoings.

The United States Supreme Court has held that in the context of criminal investigations the public interest in solving crime outweighs the interests of individuals.²⁶ How will the public interest be served if or when DNA profiling techniques become as effortless as the rapid DNA detection techniques depicted in the futuristic movie *Gattaca*?²⁷ DNA profiling could be used to limit access to high security areas of firms,

¹⁹ William Raub, Implications of Genetic Testing, FDCH CONGRESSIONAL TESTIMONY (Apr. 21, 1999). See also CLARISA LONG, MICHAEL S. WATSON & KAREN ROTHENBERG, GENETIC TESTING AND THE USE OF INFORMATION (1999).

²⁰ Weaver, *supra* note 11, at 245.

²¹ Neil A. Holtzman & David Shapiro, *Genetic Testing and Public Policy*, 316 BRIT. MED. J. 852-57 (1998).

²² Holtzman & Watson, *supra* note 9, at 17.

²³ One study demonstrated that almost one-third of genetic tests for colon-rectal cancer were misinterpreted by physicians. Jean Hellwege, *Genetics, Reproduction and The Law*, A.B.A. J., July 1999, at 20, 21 (interviewing Lori Andrews, Director of the Institute for Science, Law and Technology at the Illinois Institute of Technology).

²⁴ Jendusa, *supra* note 12, at 171.

²⁵ *Id.*

²⁶ For example, in *Schmerber v. California*, 384 U.S. 757, 770-72 (1966), the Supreme Court held that a warrantless blood test was a search and seizure under the Fourth Amendment, but was constitutional nonetheless under a balancing test of interests. With regard to the balancing test, see generally, ALDERMAN & KENNEDY, *supra* n. 8, at 30.

²⁷ *Gattaca* (Danny DeVito, Michael Shamberg & Stacey Sher, producers, 1997). The film depicted a society in which genetically engineered persons were given all the benefits of society while those deemed genetically inferior were prevented from achieving success.

defense contractors, government institutions, hospitals, child day care facilities, banks, and prisons. Limited access to such areas arguably might be in the best interests of society. On the other hand, quick and cheap DNA profiling could be used to exclude any person deemed genetically inferior from entering a particular career; such was the case of those wishing to enter the space exploration profession in *Gattaca*. Genetic makeup took precedence over ability and performance or any other more direct predictors of job success. Given this possibility, vigilance in the use of DNA evidence is called for.

B. GENETIC MONITORING

Genetic monitoring involves periodically testing groups of individuals in order to examine changes in their genetic makeup over time. For example, lung and testicular cancers exhibit genetic markers as they develop and have been linked to environmental causes.²⁸ Also, common industrial chemicals such as lead, asbestos, arsenic, and nickel are known to cause chromosomal damage.²⁹ In the employment context, genetic assessment of workers potentially could detect dangerous exposure to hazardous chemicals or radioactive substances. Employers or government agencies might justify these procedures as workplace safety measures, and on the surface, the procedures would appear appropriate and effective measures to identify hazardous work conditions.

However, medical testing of employees tends to highlight any competing interests. For example, in 1978, the National Institute for Occupational Safety and Health (NIOSH) received a request for a Health Hazard Evaluation from an authorized representative of the employees of a Westinghouse Electric Corporation plant because the workers suspected toxic chemical exposure.³⁰ The corporation, purportedly on behalf of all employees, refused the agency access to employee medical records, contending access would violate the employees' Constitutional right to privacy.³¹ The United States filed a petition to compel the corporation to comply with NIOSH inquiry. The district court ordered the company's full cooperation.³² On appeal, the Third Circuit Court of Appeals agreed with the trial court that the strong public interest in facilitating government research on workplace safety justified the minimal intrusion in the privacy of employees.³³

Society might benefit from genetic monitoring if chromosomal changes were linked to contaminated food or water supplies and unhealthy living environments (e.g., living next to a lead smelter or hazardous waste facility). Beyond the context of the workplace, data obtained from large-scale genetic monitoring projects could indicate increasing levels of environmental hazards and help identify sources of pollution, advancing the claims of those who advocate stronger environmental legislation. Yet, the history of toxic tort cases indicate that despite knowledge of many linkages between toxic substances,

²⁸ Weaver, *supra* note 11, at 246.

²⁹ *Id.*, at 243.

³⁰ United States v. Westinghouse Elec. Corp., 483 F.Supp. 1265, 1266-67 (W.D. Penn. 1980).

³¹ *Id.*

³² *Id.*

³³ United States v. Westinghouse Elec. Corp., 638 F.2d 570, 580 (3rd Cir. 1980). In spite of endorsing the intrusion by NIOSH into the privacy of employees, the appellate court remanded the case to the district court to rule on claims by employees who objected to the investigation because of privacy concerns.

chromosomal damage, and disease, defendants argue against causation and, more often than not, win. In other words, well-founded scientific evidence does not always prevail in court. Broad-based genetic monitoring certainly awakens the specter of Orwell's menacing "Big Brother."³⁴

C. CURRENT STATUS OF GENETIC TESTING

Hundreds of genetic tests are in routine use for diagnosis of disease and frequent genetic advances are presented to the general public.³⁵ Most are in the form of clinical laboratory services and some are marketed directly to the public. These procedures have shown that every human being has from 5 to 30 "misspellings," alterations, or flaws in his or her DNA, some of which may be important in predicting future disabling diseases relevant to work situations.³⁶ Many more genetic tests are under development, and their number and variety are expected to grow rapidly over the next decade.³⁷

III. ETHICAL AND LEGAL IMPLICATIONS OF GENETIC TESTING IN EMPLOYMENT

Genetic testing is likely to be accompanied by problematic consequences and is likely to raise a host of complex legal, ethical, and related social issues that have yet to be fully confronted by judicial or political means. Importantly, any discussion of bioethics must differentiate critique of the technology from critique of ethics and legalities. Specifically, a critique of the scientific technique of genetic testing is not the same as a critique of either the ethics of the potential applications of a technique or the legal responses to a scientific technique.³⁸ A critique of the scientific technique of genetic testing requires an examination of the underlying scientific method that led to the development of the technique and a critique of genetic testing methods. Some object to breaking the code of the human genome because the knowledge gleaned could pose a significant threat to basic human liberties if used for improper purposes.³⁹

One threatened abuse of genetic information is for the state or others to promote a program of eugenics, i.e. manipulating evolution to produce ostensibly more skilled

³⁴ GEORGE ORWELL, 1984 (1956).

³⁵ See e.g., the cover story for the July 10, 2000 issue of TIME was titled *Cracking the Code: The Inside Story of How These Bitter Rivals Mapped Our DNA, The Historic Feat That Changes Medicine Forever*. Shortly thereafter, the July 24, 2000 issue of TIME cover story was titled *The New Science of Alzheimer's: The Drugs; The Genetics; The Latest Theories; What You Can Do Now*.

³⁶ Holtzman & Watson, *supra* note 11, at 8.

³⁷ *Id.*

³⁸ Shapiro, *supra* note 8, at 27.

³⁹ Sheldon W. Samuels, *Genetic Testing in the Workplace: A Caste System for Workers?*, WORKINGUSA, May-June 1999, at 83-92. See also Diane B. Paul, *Is Human Genetics Disguised Eugenics?* in GENES & HUMAN SELF KNOWLEDGE 67 (Robert F. Weir, et al., eds., 1994). But c.f., Mary Z. Pelias & Nathan J. Markward, *The Human Genome Project and Public Perception: Truth and Consequences*, 49 EMORY L.J. 837, 855-57 (2000).

people by advocating programs for the biological “improvement of humanity.”⁴⁰ Genetic typing as the basis for imposition of social sanctions, including restricted mating, social and political mobility, and even permitting “socially acceptable” (but preventable and unnecessary) death, has long been a perceived threat to humankind.⁴¹ Some critics question whether current genetic testing is being designed to find genetic “defects” among job applicants, or to remove “susceptibles” from their jobs who test sensitive to a chemical or physical agent in the work environment.⁴²

In American society places great stock in expanding scientific horizons. The knowledge barrier already has been broken. The impact of genetic testing capabilities is readily seen in the context of reproductive technology. In questions about paternity, DNA profiling has become a standard technique, although many state laws prohibit or strictly limit the admissibility of genetic testing results in paternity suits.⁴³ Furthermore, some malpractice cases filed against doctors by parents of children born with genetic diseases have alleged that the physicians failed to inform the parents about genetic testing or negligently performed the tests.⁴⁴ Recognized in 22 states and the District of Columbia, “wrongful birth” actions can be brought against doctors, genetic counselors, and genetic testing laboratories.⁴⁵ The question arises, then: are these lawsuits essentially efforts to control who is genetically sufficient to be born?

If society permits genetic testing to determine paternity or to prevent the birth of a child with a serious genetic defect, then the *existence* of the genetic code and the technique of genetic testing is a moot point; the matter is debatable, but effectively has been resolved. Thus, a critique of the scientific technique of genetic testing is not the primary focus of this article. Rather, the remainder of this section addresses the ethical and legal evaluative dimensions related to genetic testing within the employment context and address the question: what ethical and legal issues may be expected to emerge within the employment context and how should society respond to such concerns?

For centuries, society has permitted testing of individuals to categorize and differentiate one individual from another. American society approves testing children and assigning grades throughout their schooling. Likewise, the courts have sanctioned pre-employment psychological tests and drug screening of job applicants for many decades. Therefore, *testing* is not the primary issue for legal and ethical debate. What is of interest

⁴⁰ Paul R. Ehrlich, *The Tangled Skeins of Nature and Nurture in Human Evolution*, CHRON. HIGHER EDUC., Sept. 22, 2000, at B8, B7-11. For a discussion, see Diane B. Paul, *Is Human Genetics Disguised Eugenics?*, in GENES & HUMAN SELF KNOWLEDGE 67 (Robert F. Weir, et al., eds., 1994); GEORGE P. SMITH II, GENETICS, ETHICS & THE LAW 104-06 (1981).

⁴¹ These beliefs are popularly thought to have been unique to the “far right,” associated with the *rassenhygiene* of the Nazis in the 1930’s. Exhibited in the current generation with the racist beliefs of neo-Nazis and white supremacists, the concept may not be restricted to a few copycat fascists on the fringes of society. See Samuels, *supra* note 38 and Pelis & Markward, *supra* note 38.

⁴² Samuels, *supra* note 38.

⁴³ For example, Pennsylvania gives almost conclusive effect to a statutory presumption that a husband is presumed to be the father of a child born to his wife. Officially, the presumption protects the child. In the paternity case of *Miscovich v. Miscovich*, 688 A.2d 726 (Pa. App. Ct. 1997), *aff’d*, 720 A.2d 764 (Penn. 1998), results of genetic testing were deemed inadmissible and, thus, the presumption stood. However, the Uniform Parentage Act, adopted by most states, allows blood tests and DNA analysis to rebut the presumption of paternity. See William C. Smith, *Daddy No More*, A.B.A. J., July 1999, at 30.

⁴⁴ Hellwege, *supra* note 23, at 21.

⁴⁵ *Id.*

is how testing relates to important human concerns. The remainder of this section addresses how genetic testing relates to two of these concerns: privacy and discrimination.

A. PRIVACY

The United States Constitution does not use the word “privacy,” though most Americans believe that privacy is a constitutional right guaranteed by the Founding Fathers.⁴⁶ Privacy has been a societal concern since 1890, when Samuel D. Warren and Louis D. Brandeis wrote a scathing article about the media and created the “right to privacy.”⁴⁷ Privacy in the workplace has been a focal point of legal battles for nearly a quarter of a century. However, the increased capability of surveillance technology has heightened both the ability of an employer to access the private activities of employees and awareness of the privacy issue. These concerns have re-emerged as a major issue for citizens in recent years.⁴⁸ Everything from e-mail at the office and unauthorized use of social security numbers to the ability of organizations to track consumer purchases are being scrutinized.

Privacy may be defined as a person’s ability to control the terms under which his or her personal information is acquired, disclosed, and used.⁴⁹ In the private sector, a state statute or a common-law right to privacy protects individuals from the tort (damage or willful wrongdoing) of invasion of privacy. Though states vary widely with regard to how an individual’s right to privacy is protected, there is some consistency. In general, persons alleging that private individuals or firms violated the right to privacy must claim at least one of four distinct, though related torts: (1) intrusion upon the person’s seclusion or solitude, (2) public disclosure of embarrassing private facts about the person, (3) publicity that places the person in a false light in the public eye, and/or (4) appropriation, for another person’s advantage, of the person’s name or likeness.⁵⁰ The acquisition or use of DNA information in a given context could conceivably implicate all four of the privacy torts. Some authorities indicate that there is little doubt that the courts will establish a legal privilege that could be labeled an individual’s “right to genetic privacy.”⁵¹

In 1967, the Supreme Court interpreted the Constitution in the landmark case of *Katz v. United States*.⁵² The Court declared that the Fourth Amendment protects an individual’s right to privacy “against certain kinds of governmental intrusions.”⁵³ More importantly, in *Katz* the Supreme Court held that the Fourth Amendment protects people,

⁴⁶ ALDERMAN & KENNEDY, *supra* note 8, at i.

⁴⁷ Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV.L.REV. 193 (1890).

⁴⁸ Jedediah Purdy, *An Intimate Invasion*, USA WEEKEND, June 30-July 2, 2000, at 6-8.

⁴⁹ ALAN F. WESTIN, *PRIVACY & FREEDOM* (1967). See also, Warren & Brandeis, *supra* note 47 (stating that the right to privacy is the “right to be let alone”).

⁵⁰ William L. Prosser, *Privacy*, 48 CAL.L.REV. 383, 389 (1960). See also RESTATEMENT (SECOND) OF TORTS, §§ 652A-E (1977).

⁵¹ Hugh Miller, III, *DNA Blueprints, Personhood and Genetic Privacy*, 8 HEALTH MATRIX: J. L & MED. 179-202 (1998).

⁵² *Katz v. United States*, 389 U.S. 347, 1967 U.S. LEXIS 2 (1967).

⁵³ *Id.* at 360.

not places.⁵⁴ Though *Katz* concerned a government wiretap, the Fourth Amendment jurisprudence developed in *Katz* applies to any suspected government intrusion on an individual's privacy.

Privacy includes the right to be free from unreasonable search and seizure.⁵⁵ When faced with an employee's invasion of privacy claim, a court assesses the employee's expectation of privacy in the workplace and weighs the expectation against the intrusiveness of the employer's search and reasoning for the search. Employers argue that they have a substantial interest in maintaining security in the workplace and that the employee has waived a right to privacy by accepting employment.⁵⁶ Lawsuits alleging an invasion of privacy in the workplace usually favor the employer rather than the employee, especially if the employee has signed an agreement acknowledging the employer's right to surveillance.⁵⁷ However, in response to electronic surveillance of employee communications, a few states have passed laws to limit surveillance of employees and an amendment to the federal wiretap statute established limits on when firms can intercept electronic messages of their employees.⁵⁸

Critics of genetic testing believe there will be many temptations to pry into others' genomes. Suppose in the near future an enterprising reporter acquires a cocktail napkin used by a presidential candidate, analyzes the DNA left behind, then publishes the news that the candidate is at risk for cancer, heart disease, or another debilitating affliction. Might this affect election results? Would such information, if available in 1984, have affected the reelection of Ronald Reagan who subsequently developed Alzheimer's? Is it appropriate to make such information public?

The first federal court case to address the issue of genetic privacy was *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*.⁵⁹ Operated by the Regents of California and under contract with the United States Department of Energy, Lawrence Berkeley Laboratory (Lawrence Labs) required all applicants to undergo employment entrance examinations. The plaintiffs in the case applied for employment at Lawrence Labs and, as part of the entrance examination, completed a medical history questionnaire and provided blood and urine samples. Lawrence Labs secretly tested the blood and urine of the African-American applicants for sickle cell carrier status, but did not screen white applicants for genetic disorders. Test results were placed in the employment files of the workers, but were not disclosed to them.

In *Norman-Bloodsaw*, the United States Court of Appeals for the Ninth Circuit held that employers who conduct nonconsensual medical testing can be liable for invasion of privacy under the United States and California Constitution. The court flatly rejected the

⁵⁴ *Id.* at 351.

⁵⁵ Michael Higgins, *High Tech, Low Privacy*, A.B.A. J., May 1999, at 52, 54-55.

⁵⁶ *Id.*

⁵⁷ *Id.* at 54, 57. See *Vega-Rodriguez v. Puerto Rico Telephone Co.*, 110 F.3d 174 (1st Cir. 1997) (employees had no expectation of privacy while working in an office area shared with other workers); *Smyth v. Pillsbury Co.*, 914 F. Supp. 97 (E.D. Pa. 1996) (employee had no privacy interests when voluntarily using the company e-mail system to communicate unprofessional comments).

⁵⁸ See Higgins, *supra* note 55, at 54, 57. See also Electronic Communications Privacy Act of 1986, 18 U.S.C. §§ 2510-2522. See also *Dorris v. Absher*, 959 F. Supp. 813 (M.D.Tenn. 1997) (employees successfully sued an employer under the federal wiretap statute for secretly recording the employees' conversation).

⁵⁹ 135 F.3d 1260 (9th Cir. 1998).

employer's argument that the employees had consented to the tests by agreeing to the physical and giving blood and urine samples. Moreover, the court held that because of the differential impact on African-Americans, if the illicit testing was proven at trial, the conduct would constitute job discrimination in violation of Title VII of the Civil Rights Act of 1964.⁶⁰ The appellate court flatly rejected the trial court's reasoning that the employees had consented to the tests by agreeing to the physical and giving blood and urine samples. Judge Stephen Reinhardt wrote, "One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic makeup."⁶¹

Following *Norman-Bloodsaw* was a case regarding testing for HIV, the genetic indicator for a predisposition to AIDS. In *Doe v. High-Tech Institute, Inc.*,⁶² a school required all students to undergo blood testing for rubella. One student signed a consent form for testing for rubella, but an instructor requested the laboratory test the student's sample for HIV. The student successfully sued the school under invasion of privacy.

An individual's DNA blueprint contains a vast amount of information about people's biologically determined characteristics. Though much of it is currently undecipherable, scientists detect genetic markers that indicate susceptibility to an increasing number of hereditary diseases. As genetic knowledge increases, DNA blueprints will prove to have increasingly significant medical implications for the diagnosis and treatment of diseases and some have likened such a blueprint to a probabilistic "future diary" of an individual's projected life history.⁶³

At the same time, the case for giving DNA information heightened protection under the right to privacy is not necessarily limited to its conjectured predictive power concerning an individual's future life history. State and federal circuit courts have extended the privacy right to encompass a variety of infringements against the particular manifestations of individuals' identity besides the paradigm cases of unwarranted intrusions into his diary, personal records, or private behavior. Such infringements include expropriation of a person's name,⁶⁴ photograph, or likeness;⁶⁵ a person's signature;⁶⁶ and voice or even a likeness of a person's voice.⁶⁷ Hence, it may appear that information about an individual's DNA blueprint deserves special protection under the right to privacy, notwithstanding its conjectured predictive strength. For example, as Catherine Valerio Barrad stated: "[An] individual's genetic profile is even more innately an attribute of his identity than is his likeness or his voice, since the latter are merely physical expressions of genetic information. If one's face, physical features, and voice are so intrinsic to the individual as to be protected as inviolate, then the genetic

⁶⁰ *Id.*

⁶¹ *Id.* at 1269.

⁶² *Doe v. High-Tech Inst., Inc.* (No. 97CA0385, 1998 WL 379926 (Colo. Ct. App. July 9, 1998)).

⁶³ George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded 'Future Diaries,'* 270 JAMA 2346 (1993).

⁶⁴ *Vanderbilt v. Mitchess*, 67 A. 97 (N.J. 1907).

⁶⁵ *Motschenbacher v. R.J. Reynolds Tobacco Co.*, 498 F.2d 821,825 (9th Cir. 1974).

⁶⁶ *United States Life Ins. Co. v. Hamilton*, 238 S. W.2d 289, 292 (Tex. Civ. App.-- Waco 1951, error ref'd n.r.e.).

⁶⁷ *Midler v. Ford Motor Co.*, 849 F.2d 460, 463 (9th Cir. 1988).

determinates of those attributes must be the true expression of identity and also protected against appropriation.”⁶⁸

Privacy dilemmas arise, however, when individuals decline to know relevant information or, knowing it, refuse to share it with others who may also need to know. Developments in genetics have led to a greater understanding of the inter-relatedness of individuals and the way in which the interests on one family member cannot be entirely isolated from the interests of others.

Because of shared DNA, one person's susceptibility to a genetic disorder means that other blood relatives will also be at risk of developing that disorder. Awareness of being a carrier of a genetic disorder alerts one to the fact that the same risks apply to siblings. A woman who has a son with Duchenne Muscular Dystrophy and has tested positive for carrier status, for example, has information that is clearly relevant to her sister in planning her own family. In such circumstances, few decisions are entirely personal.

When genetic information is revealed about one individual it often releases information about others. One person's rights to genetic privacy and medical confidentiality may conflict with the rights of siblings or other relatives to have the knowledge that would permit them to exercise a right of choice. As soon as one has information about one's own genetic heritage, information about relatives can usually be inferred. This interconnectedness of interests has led some commentators to suggest that a person or patient should be seen as a “family” rather than as an individual. The Royal College of Physicians in the United Kingdom, for example, suggests that: “because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes, and who need the information in order to find out their own genetic constitution. If so, an individual's prima facie right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information about themselves.”⁶⁹

A New Jersey appeals court ruled consistent with this view. When a woman with familial adenomatous polyposis brought suit against the estate of her deceased father's deceased doctor for not warning relatives of their risk 20 years earlier, the court remanded the case for trial to determine whether the duty to warn relatives was breached.⁷⁰ Thus, the limits of privacy relevant to genetic testing have yet to be fully explicated by law.

B. DISCRIMINATION

Suppose an employer takes a blood sample for a physical exam and decides to check risk factors for crippling (and costly) diseases. Found through an examination of the genetic code is that the employee is at risk of a catastrophic disease. How does the employer react? Insurance companies might inflate premiums or limit coverage for individuals known to have a genetic predisposition towards given disorders, such as Huntington's Disease, or for those who have increased susceptibility to particularly

⁶⁸ Catherine M. Valerio Barrad, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1047 (1993).

⁶⁹ ROYAL COLLEGE OF PHYSICIANS, ETHICAL ISSUES IN CLINICAL GENETICS ¶ 4.10 (1991).

⁷⁰ *Safer v. Pack*, 677 A.2d 1188 (N.J. 1996).

virulent cancers. Similarly, an employer might refuse to hire an individual on the basis of this genetic information. Or, more subtly, the organization may decide to make an employee's life at work so stressful and difficult that the employee quits. In these cases the organization potentially may save a considerable sum of money by eliminating the employee from the payroll.

The concern is that information about alleged defects in an individual's genetic blueprint could be used to discriminate against that individual in employment or insurance contexts.⁷¹ Is this a legitimate fear? Scientists working with the Council for Responsible Genetics have identified over 200 cases in which healthy individuals were denied insurance or employment based on genetic testing. Unfortunately, the same technology that can be used to help doctors identify and treat illness is also being misused to discriminate against people perceived to be at risk for future ill health.⁷² Individuals who might otherwise believe that they can benefit from genetic testing may decline because of fearing loss of insurance, substantially higher premiums, or employment discrimination.

It is accepted policy for health insurers to exclude people with pre-existing disorders. Genetic testing provides an enormous opportunity for classifying numerous diseases or other medical conditions as pre-existing because they have their roots in the genes of prospective insureds. At first glance, such a policy might seem reasonable, akin to charging smokers higher rates. Insurance is based on the concepts of risk-spreading and risk-sharing. When most people's future health risks are unknown, the future health care costs of a group can be predicted on an aggregate, actuarial basis and the costs spread across the entire group. But, with genetics technology beginning to identify which individuals in a group are likely to develop particular diseases, insurance companies have begun to target them for higher rates or denial of coverage. Carried to the extreme, everyone could be uninsurable, since every human being carries "defective" genes that may trigger various medical disorders.

Fears of discrimination in health insurance and employment are intertwined. Without employment most Americans do not have the means of obtaining health insurance. Yet, genetic information in the workplace poses unique challenges. Employers in most jurisdictions are not prohibited from requiring genetic testing, even though there is insufficient evidence to justify the use of any existing test for genetic susceptibility as a basis for employment decisions. Even if employers do not use genetic information, they still may have access to the medical records of their employees and prospective employees, and thus will be able to discover if these persons have certain health hindering predispositions.

⁷¹ Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74, B.U. L. REV. 1, 2-3 (1994).

⁷² Wendy L. McGoodwin, *Genetic Testing: A Tool for Doctors, Not for Insurers*, 15 J. INS. REG. 71-75 (1996).

IV. CURRENT LAW

A. STATE REGULATORY ACTIVITIES

The interest of insurance companies and employers in genetic information has aroused a countercurrent of public pressure for restrictions on the use that can be made of genetic diagnostic information.⁷³ Such pressure has generated enough concern to stimulate legislatures at both the state and federal levels to enact laws curtailing the acquisition and use of genetic information.

The first law addressing genetic discrimination in the workplace was enacted in 1975 when North Carolina passed legislation prohibiting employers from discriminating against any person possessing the traits for sickle cell or hemoglobin C.⁷⁴ Over the next decade, other states passed laws prohibiting employment discrimination based on sickle cell, other specified traits, and carrier status.⁷⁵ In 1989, Oregon revised a law prohibiting employers from subjecting employees or prospective employees to breathalyzer or polygraph testing, and added a prohibition against genetic testing.⁷⁶ Although Oregon did not define genetic testing until 1995, it was the first state to law to go beyond specific traits and disorders.⁷⁷ More comprehensive legislation emerged in 1991, when a Wisconsin law prohibited workplace discrimination and employer access to genetic test results, along with providing privacy protections for employees.⁷⁸ Wisconsin's legislation addressed not only employers but also labor organizations, employment agencies, and licensing agencies. The focus of the legislation was on genetic testing and was not on the use of genetic information derived from phenotype (observable characteristics) indicators and family history. The legislation provides for genetic testing of an employee if the employee requests the test. The law also requires written and informed consent and

⁷³ Tony McGleenan, *Genetic Information and The Challenge to Privacy*, 12 INT'L REV. L. COMPUTERS & TECH. 535-47 (1998).

⁷⁴ N.C. GEN. STAT. § 95-28.1 (2000)(prohibiting discrimination based on genetic testing or genetic information).

⁷⁵ Florida, New Jersey and New York. FLA. STAT. § 760.40 (2001)(generally requiring prior informed consent and confidentiality to lawfully perform DNA analysis) and FLA. STAT. § 627.4301 (2001) (prohibiting health insurers from using genetic information for discriminatory purposes); N.J. STAT. § 10:5-12 (2001) (amended to declare that discrimination based upon genetic information, atypical hereditary cellular or blood traits of any individual, or the refusal to submit to a genetic test or make available the results of a genetic test to an employer is an unlawful employment practice); N.Y. EXEC. § 296 (Consol. 2001) (prohibiting employers from discriminating against an individual based on the individual's genetic predisposition or carrier status). Comments to the law indicate that the New York legislature feared that advances in genetic testing for disease, predisposition to disease or carrier status raised the possibility that certain individuals could be labeled genetically "defective" and that a genetic underclass of society would result from such discrimination.

⁷⁶ OR. REV. STAT. § 659.227 (1999).

⁷⁷ OR. REV. STAT. § 659.700-720 (1995) (establishing definitions, rights and responsibilities pertaining to genetic testing and genetic information).

⁷⁸ WIS. STAT. §§ 111.372 (1991) (proscribing use of genetic testing and information in employment and other circumstances).

specifies that no adverse action may be taken against the employee as a result of the procedure. Employee testing may only be conducted for the purpose of investigating workers' compensation claims or to determine employees' susceptibility or level of exposure to toxic chemicals in the workplace. Wisconsin's criminal code specifically makes it unlawful to disclose genetic information without the written and informed consent of the individual.⁷⁹

Thus, the Wisconsin approach integrates protection against discrimination in employment with some privacy protection. Similar approaches have been incorporated to varying degrees in recent legislation passed in Iowa,⁸⁰ Rhode Island,⁸¹ New Hampshire,⁸² New York,⁸³ and Oregon.⁸⁴ This trend parallels similar state initiatives in the health insurance context.⁸⁵

In 1996, New Jersey enacted comprehensive legislation that prohibits employment discrimination based on genetic information.⁸⁶ Thus, the New Jersey legislation does not focus on genetic testing alone but expands the prohibition to include discrimination on the basis of information about genes, gene products, or inherited characteristics that may derive from an individual or family member.⁸⁷ New Jersey also prohibits retaliation by employers if employees or prospective employees refuse to take genetic tests or refuse to reveal results.

In contrast, a New York law specifies that employers may "...require a specified genetic test as a condition of employment where such a test is shown to be directly related to the occupational environment, such that the employee or applicant with a particular genetic anomaly might be at an increased risk of disease as a result of working in said environment."⁸⁸ The law is silent on the need for informed and written consent of employees or applicants. Even when state laws require informed consent before genetic testing, they do not address whether the informed consent process will provide notice that the test results may be disclosed without authorization under certain circumstances, including determining paternity, criminal proceedings, or health department protocols. "There's a lot of legislation at the state level, but there aren't a lot of cases yet," declared Terry Moorhead Dwokin, chairwoman of business law at the Indiana University Kelly School of Business.⁸⁹

⁷⁹ *Id.* § 942.07 (1991).

⁸⁰ IOWA CODE § 729.6 (1992).

⁸¹ R.I. GEN. LAWS §§ 28-6.7-1, 28-6.7-3 (1992).

⁸² N.H. REV. STAT. ANN. §§ 141-H:1, 141-H:3 (1995).

⁸³ New York, NY A:7839 (1996).

⁸⁴ OR. REV. STAT. §§ 659.036, 659.227, 659.700, 659.705 (1995).

⁸⁵ Kathy L. Hudson & Karen H. Rothenberg,, *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, 270 SCIENCE, 391-94. (1995).

⁸⁶ New Jersey Genetic Privacy Act, N.J. STAT. ANN. § 695 (1996).

⁸⁷ *Id.* at 20.

⁸⁸ NY A:7839 (1996).

⁸⁹ Greg Jefferson, *Legalities, High Cost Hinder Genetic Testing*, INDIANAPOLIS BUS. J., Feb. 21, 2000, at 1-3 (quoting Terry Dwokin).

B. FEDERAL INITIATIVES

The major legislation that governs genetic screening or monitoring by private employers is the Americans with Disabilities Act of 1990 (ADA).⁹⁰ Additionally, a number of other laws can affect the private sector. The ADA prohibits discrimination against “a qualified individual with a disability” in the context of “job application procedures, the hiring, advancement or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment.”⁹¹ The ADA has two potential applications to the issue of genetic screening and monitoring. First, and most importantly, the ADA could treat a genetic defect as a disability that would be worthy of protection under the Act. Second, the ADA could prevent an employer from using genetic screening or monitoring of employees or job applicants to determine if they have a genetic defect. If either assertion is correct, the ADA could provide powerful protection for individuals not wishing to undergo genetic monitoring or screening. Each issue is discussed below.

1. GENETIC DEFECTS AS DISABILITIES

Much debate has surrounded the question of whether the ADA covers genetic defects, but courts have yet to rule on the issue.⁹² Under the ADA, federal regulations have created a three-part definition for the term disability: “Disability means, with respect to an individual (1) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (2) a record of such an impairment; or (3) being regarded as having such an impairment.”⁹³

A genetically caused illness potentially could be considered a physical or mental impairment if the underlying genetic defect has manifested itself. A number of genetically based illnesses have already been classified as disabilities under the ADA. These diseases, which include muscular dystrophy and multiple sclerosis, were mentioned as covered diseases in the legislative history of the Act. If the genetic defect has not yet manifested itself as an illness, it would not be considered an impairment under the first part of the definition since it would not have substantially limited the individual.

With genetic defects uncovered through genetic monitoring or screening, an individual could be discriminated against even though he or she does not manifest any symptoms of the disease. The defect would only provide a potential for a future impairment. Therefore, even though a number of illnesses with genetic causes have been classified as genetic defects, this factor does not conclusively determine that discrimination based on the discovery of any genetic defect is considered a disability under the ADA.

⁹⁰ 42 U.S.C. §§ 12101-12213 (1995).

⁹¹ *Id.* §12112(a).

⁹² Frances H. Miller & Philip A. Huvos, *Genetic Blueprints, Employer Cost-Cutting, and The Americans with Disabilities Act*, 46 ADMIN. L.REV. 373-82 (1994); M. R. Natowicz, et al., *Genetic Discrimination and the Law*, 50 AM. J. HUMAN GENETICS 470-73 (1992).

⁹³ 29 C.F.R. § 1630.2(g) (1996).

On the other hand, the third aspect of the definition could provide potential protection for individuals with genetic defects.⁹⁴ Under the ADA, an individual who is “regarded as” having an impairment receives protection from discrimination.⁹⁵ This language suggests that an individual could receive protection from discrimination on the basis of an impairment, even if that individual does not currently have the impairment. An individual found to have a genetic defect and who is refused a job based on the condition that could arise because of the defect could be protected under the ADA if the employer regarded the potential employee as having that condition.

In 1995 the Equal Employment Opportunity Commission (EEOC), the agency in charge of enforcing the ADA, issued a guideline in its compliance manual on the definition of “disability” that addresses genetic discrimination in the workplace. The guideline states that the ADA would protect individuals subjected to discrimination on the basis of genetic information relating to illness, disease or other disorders.⁹⁶ To further clarify its position, the EEOC cited as an example an individual with a positive predictive genetic test for colon cancer as being subject to protection under the ADA if the employer “regards” the individual as having a disability and has discriminated against the individual because of that perception.

Recently, the EEOC filed its first court action challenging genetic testing, a petition for a preliminary injunction against Burlington Northern Santa Fe Railroad, to end genetic testing of employees who have filed claims for work-related injuries based on carpal tunnel syndrome.⁹⁷ In its petition, filed in U.S. District Court for the Northern District of Iowa, the EEOC asked the court to order the railroad to end its nationwide policy of requiring employees who have submitted claims of work-related carpal tunnel syndrome to provide blood samples which are then used for a genetic DNA test for Chromosome 17 deletion, which is claimed to predict some forms of carpal tunnel syndrome.

The company began the testing program in the year 2000 on the advice of its medical department to identify those individuals for whom the disability was not work-related but was due to the absence of Chromosome 17. The EEOC also sought to halt any disciplinary action or termination of the employee who has refused to submit a blood sample.

EEOC Commissioner Paul Steven Miller explained, “The Commission takes the position that basing employment decisions on genetic testing violates the ADA. In particular, employers may only require employees to submit to any medical examination if those examinations are job-related and consistent with business necessity. Any test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee’s present ability to perform his or her job.”⁹⁸

The situation is strikingly similar to discrimination of individuals with asymptomatic HIV. These individuals frequently develop full-blown AIDS, but do not manifest any present symptoms. Because of the fear surrounding the transmission of HIV, many

⁹⁴ Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J. L. & MED. 109-13 (1991).

⁹⁵ 29 C.F.R. Section 1630.2(g)(3) (1995).

⁹⁶ EEOC, 2 COMPLIANCE MANUAL § 902, Order 915.002, 902-45 (1995).

⁹⁷ See <http://www.eeoc.gov/press/2-9-01-c.html>.

⁹⁸ *Id.*

individuals with asymptomatic HIV are discriminated against even though they do not show symptoms of AIDS. The interpretative guidelines accompanying the ADA have stated that asymptomatic HIV individuals are considered disabled for the purposes of the ADA. Numerous courts have upheld this interpretation.⁹⁹ Similarly, individuals with genetic defects may have no current symptoms of their underlying defect, but may be discriminated against because individuals regard them as being disabled. The treatment under the ADA of these similarly situated individuals gives strong support for genetic defects being included under the ADA's definition of a disability.

Additionally, other cases involving individuals with latent conditions that were decided under the ADA further support this interpretation. For instance, in *Munoz v. H & M Wholesale, Inc.*¹⁰⁰ a truck driver was fired from his job because the employer was afraid that continued driving would re-aggravate the driver's previous back injury. The court determined that although Munoz had previously injured his back, he was not suffering from a present back condition that would prevent him from performing "an entire class of jobs."¹⁰¹ However, the court also found that H & M Wholesale, Inc. regarded Munoz as having a disability because it was afraid that he could potentially reinjure his back.¹⁰² Therefore, the court determined that Munoz satisfied the definition of disability under the ADA. Even though no present disabling condition existed, the future possibility of such a condition satisfied the ADA's definition of a disability.

These cases demonstrate that individuals without present disabling conditions can be considered disabled because of their potentially disabling conditions. In light of these cases, the comparison to individuals with asymptomatic HIV and the EEOC's interpretation of the ADA's definition of disability as including a latent genetic defect, courts may determine that individuals with latent genetic defects could be considered disabled under the ADA. However, some courts have been reluctant to use the "perception" of disability when requiring ADA coverage. For instance, in *EEOC v. R. J. Gallagher Co.*, the plaintiff alleged that he had been fired in part because of developing leukemia.¹⁰³ In rejecting his claim, the court wrote: "As usual in these cases, when the record shows no actual disability the worker claims the employer perceived him as disabled. Assuming that Gallagher [the employer] perceived Boyle [the employee] as ill, that is not a perception of disability. The 'or perceived' language is in the law to protect people who have some obvious specific handicap that employers might generalize into a disability. Boyle did not have a condition—a defect that Gallagher, based on erroneous social stereotypes, could generalize into an inability to function on the job."¹⁰⁴

If a genetically caused illness is found to be considered a disability under the ADA, the range of protections would be quite broad. The employee or applicant would have the opportunity to be hired, compensated, and classified as any other employee. The employer would also carry the burden of making sure that work arrangements, conditions, and rules did not discriminate or tend to discriminate against genetically

⁹⁹ See, e.g., *Abbot v. Bragdon*, 912 F. Supp. 580 (D. Me. 1995).

¹⁰⁰ 926 F. Supp. 596 (S.D. Tex. 1996).

¹⁰¹ *Id.* at 606.

¹⁰² *Id.*

¹⁰³ 959 F. Supp. 405 (S.D. Tex. 1997).

¹⁰⁴ *Id.* at 409.

limited individuals. If these conditions are not met, the ADA provides a valuable cause of action for employees or applicants to challenge employers' behaviors or practices.¹⁰⁵

Even though the ADA potentially offers protection from discrimination, it does not provide protection of employees' privacy. Although the ADA does prevent employers from making pre-employment medical inquiries, it does not prevent employers from obtaining medical information, including genetic information, after a conditional offer of employment. Employers can require a pre-placement medical exam, which may include a physical examination and blood tests (including genetic tests). Employers may also require a general medical release of individuals' medical records. Although employers are prohibited from discriminating on the basis of disability, it is difficult for individuals to prove that they did not get jobs or promotions because of disabilities or other genetic information.¹⁰⁶

2. EMPLOYEE TESTING UNDER THE ADA

Even if employers are not allowed to discriminate against individuals with genetic defects, employers still might require employees undergo genetic screening or monitoring to determine hyper-susceptibilities or other safety-related conditions. Under the ADA, a person with a disability must still be "qualified" in order to be able to receive or to continue a job. The ADA would allow screening or selection criteria that screen out disabled individuals if the test is "job-related for the position in question and is consistent with business necessity."¹⁰⁷ Therefore, it seems likely that employers could use certain genetic defects as part of a larger out-screening technique. For instance, in order to improve airline safety, airlines could screen out individuals likely to be prone to heart attacks.¹⁰⁸ In order to provide an acceptable work environment, companies that require employees be exposed to airborne particles, such as mine operators, could test for individuals more prone to emphysema. Individuals at risk to develop certain neurological conditions such as Alzheimer's disease could be removed from operating heavy equipment in order to promote workplace safety for all workers. Thus, private employers would still have an incentive to force employees to undergo genetic monitoring or screening, even though they cannot "discriminate" against them.

Employers would probably conduct genetic screening during pre-employment medical examinations, which are regulated under the ADA.¹⁰⁹ The statute contains a blanket prohibition against pre-employment examinations or inquiries to determine if a job applicant has a disability or to determine the severity of a disability.¹¹⁰ However, the ADA permits pre-employment inquiries to assess "the ability of an applicant to perform

¹⁰⁵ See 29 C.F.R. § 1640.13 (1996).

¹⁰⁶ Charles Siebert, *The DNA We've Been Dealt*, N.Y. TIMES, Sept. 17, 1995, at 50, 52.

¹⁰⁷ 42 U.S.C. § 12112(b)(5)(B)(6) (1996).

¹⁰⁸ In fact, the Federal Aviation Administration (FAA) has for decades implemented a policy partially in response to this problem. The FAA regulation bans any pilot over sixty from flying a commercial airliner. *Airline Pilots Assoc. Int'l v. Quesada*, 276 F.2d 892 (2d Cir. 1960), *aff'd*, 286 F.2d 319 (2d Cir. 1960), *cert. denied*, 366 U.S. 962 (1961).

¹⁰⁹ Miller & Huvos, *supra* note 92, at 378-81.

¹¹⁰ 42 U.S.C. § 12112(d)(2)(A) (1995).

job-related functions.”¹¹¹ This seems to allow for a narrow range of genetic screening during the pre-employment phase. Furthermore, the ADA allows employers to conduct certain examinations after an offer has been extended but before the applicant has begun work.¹¹² The ADA attaches a number of conditions to these exams, including requiring all employees undergo the same examination.¹¹³ Finally, the ADA repeats the provision that such examinations must be “job-related and consistent with business necessity.”¹¹⁴

These provisions seem to allow for the implementation of a company-wide genetic monitoring or screening program to improve employee health or safety. They also appear to permit the screening or monitoring of employees for genetic defects such as hyper-susceptibility for certain workplace conditions. Of course, if screening was conducted during an initial employment exam, the employment offer could not be withdrawn, but the employee could be forced to take another job with the company if the condition found affected job performance.¹¹⁵ While this may appear to be an acceptable compromise, it might exclude certain individuals from desired or valuable positions of employment.

Thus, the ADA provides a great deal of protection against genetic monitoring or screening implemented solely for discriminatory purposes, instead focusing permissible testing on business necessity. These limitations serve an important societal interest by preventing discrimination while allowing employers to protect their business needs. While these limitations might protect society at large, however, they still leave individuals vulnerable to unwanted revelations about their genetic makeup. Such discoveries can have severe psychological ramifications.¹¹⁶ Many individuals do not wish to know their genetic makeup,¹¹⁷ even if doing so would serve a socially useful goal or would help to further the business interests of employers or potential employers.

3. OTHER FEDERAL PROHIBITIONS

Title VII of the Civil Rights Act of 1964¹¹⁸ is the major legislation regulating equal employment opportunity in the United States. Title VII states that it is illegal for employers to discriminate because of race, color, religion, sex, or national origin. Because certain genes occur more frequently in particular ethnic groups, there is concern that screening could be used as an excuse for racial discrimination. For example, blacks have a higher chance of sickle cell anemia than others groups, while Jewish individuals

¹¹¹ *Id.* § 12112(d)(2)(B) (1995).

¹¹² *Id.* § 12112(d)(3).

¹¹³ *Id.* § 12112(d)(A).

¹¹⁴ *Id.* § 12112(d)(4)(A).

¹¹⁵ This situation would involve the “reasonable accommodations” provisions of the ADA, requiring employers to attempt to accommodate the disability of an individual. *Id.* § 12112(d)(4)(B).

¹¹⁶ T.M. Marteau & R. T. Croyle, *Psychological Responses to Genetic Testing*, 316 BRIT. MED. J. 693-6 (1998).

¹¹⁷ It is interesting to note that before the gene for Huntington’s was identified, 70% of those in affected families said they planned to be tested. With the gene and the death sentence that accompanies it now known, just 15% opt for knowledge over ignorance. One reason is that Huntington’s remains incurable, making the diagnosis less useful. Christine Gorman, *The Doctor’s Crystal Ball*, TIME, Apr. 10, 1995, at 60-63.

¹¹⁸ 42 U.S.C. § 2000e (1964), Pub. L. No. 88-352.

are more likely to inherit Tay-Sachs disease. Using genetic testing to screen these persons could be construed as a violation of Title VII because of the link with national origin.

In 1996, Congress passed the Health Insurance Portability and Accountability Act (HIPAA)¹¹⁹ which primarily applies to employer-based health insurance coverage and was designed to allow workers to maintain insurance coverage if they change or leave their jobs. The act applies to employers who provide health insurance coverage through self-funded plans, as well as through insurance companies, including those self-funded plans that have been beyond the reach of state legislation because of the Employee Retirement Income Security Act (ERISA) preemption.¹²⁰

HIPAA explicitly states that a presymptomatic diagnosis does not qualify as a preexisting condition,¹²¹ thereby offering a degree of protection to some seeking presymptomatic testing, and specifically prohibits a group health insurance plan from using “genetic information” to establish rules of reliability or continued eligibility.¹²² The act also provides that genetic information shall not be treated as a preexisting condition “in the absence of that diagnosis of the condition related to such information.”¹²³ Furthermore, the act does not prohibit group health plans from increasing rates, excluding all coverage for a particular condition, or imposing a lifetime maximum on benefits as long plan characteristics are not directed in individual sick employees or dependents.¹²⁴ Additionally, 26 states have passed laws barring health insurance discrimination on the basis of genetic testing or information.¹²⁵

In summary, on the federal level with respect to the private sector, the ADA, Title VII of the 1964 Civil Right’s Act, and the Health Insurance Portability and Accountability Act of 1996 appear to offer limited protection from discrimination but do not prohibit employers from gaining access to genetic information. At present, there is no uniform protection against use, misuse, and/or access to genetic information in the workplace.¹²⁶ In the public sector both the ADA and the Health Insurance and Portability and Accountability Act are applicable. However, foremost among the regulations restricting genetic testing is Executive Order 13145 signed by President Clinton on February 8, 2000, barring the federal government from using genetic information in hiring or promoting employees.¹²⁷ The order outlaws genetic tests as a precondition for employment and benefits. The order also bans using genetic information to determine promotions or disclosing that information except when necessary to provide medical

¹¹⁹ Health Insurance and Portability and Accountability Act, Pub. L. No. 104-191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of chapters 18, 26, 29 and 42 U.S.C.).

¹²⁰ See Employee Retirement Income Security Act of 1974, Pub. L. No. 93-406, 88 Stat. 829 (1974) (codified at 29 U.S.C. §§ 1001-1461)).

¹²¹ Health Insurance Portability and Accountability, Pub. L. No. 104-191, § 701(b)(1)(B), 110 Stat. 1936, 1940 (1996) (codified at 26 U.S.C. § 9801(b)(1)(B) (2001).

¹²² 29 U.S.C. § 1182(9)(1)(2000).

¹²³ 26 U.S.C. § 9801(b)(1)(B)(2001); 29 U.S.C. § 1181(b)(1)(B)(2001); 42 U.S.C. § 300gg(b)(1)(B)(2001).

¹²⁴ 26 U.S.C. § 9802(a)(2)(B)(2001); 29 U.S.C. § 1182(a)(2)(B)(Supp. III 1997). See also H.R. Rep. No. 104-736, at 406-07 (1996).

¹²⁵ R. Pear, *States pass laws to regulate use of genetic testing*, 18 N.Y. TIMES, Oct. 18, 1997, at A 1-9.

¹²⁶ Karen Rothenberg & Barbara Fuller, *Genetic Information And The Workplace: Legislative Approaches and Policy Challenges*, 275 SCIENCE 1755-57 (1997).

¹²⁷ Exec. Order No. 13145, (Feb. 10, 2000), printed in *To Prohibit Discrimination in Federal Employment Based on Genetic Information*, 36 WEEKLY COMP. PRES. DOC. 244 (Feb. 14, 2000).

treatment for those employees and when used anonymously by researchers. The order dovetails with the Genetic Nondiscrimination in Health Insurance and Employment Act that was introduced in Congress in 1999 and would essentially extend the executive order to the private sector.

4. CONSTITUTIONAL AMENDMENTS

Under the Fourth Amendment, the federal government cannot violate “[t]he right of people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures.”¹²⁸ The Fourteenth Amendment extends this protection to searches and seizures conducted by state officers.¹²⁹ A proposed government-run genetic testing program would be a search under the Fourth Amendment.¹³⁰ Therefore, the program would have to meet the “reasonableness” requirement of the Fourth Amendment search.¹³¹ To determine if a search meets the “reasonableness” requirement, a court must “balanc[e] [the search’s] intrusion on the individual’s Fourth Amendment interests against its promotion of legitimate governmental interests.”¹³²

The government might have a number of legitimate interests in conducting genetic screening or monitoring programs, such as the promotion of safety, improving the health of its citizens or workers, or making it easier to identify battlefield dead.¹³³ Courts have found important interests include the protection of school children from drugs,¹³⁴ the prevention of train accidents,¹³⁵ and ensuring the fitness of customs officials engaged in interdicting drugs and firearms.¹³⁶ In the context of genetic testing, merely informing individuals about future health concerns does not seem to be sufficient consideration for searches. Individuals should be permitted to risk not knowing of impending genetic illnesses without government involvement. On the other hand, the government often acts to protect the safety and health of its workers and its citizens, so this goal is a valid interest for the government.¹³⁷ This is markedly similar to cases in which courts have upheld government mandated drug and alcohol testing. The courts may consider the promotion of health and safety as an important governmental interest.

Courts must consider individuals’ right to privacy, with regard to genetic tests and the information uncovered by such tests. With regard to actually performing such tests, the intrusion into an individual’s right to privacy is minimal, because it involves drawing only a small amount of blood. The court has upheld similar searches against privacy

¹²⁸ U.S. CONST. amend. IV.

¹²⁹ U.S. CONST. amend. XIV. *See also* *Elkins v. United States*, 364 U.S. 206, 213 (1960).

¹³⁰ *E.g.*, *Vernonia School Dist. v. Acton*, 515 U.S. 646, 652 (1995); *National Treasury Employees Union v. Von Raab*, 489 U.S. 656, 665 (1989).

¹³¹ *Acton*, 515 U.S. at 653.

¹³² *Skinner v. Ry. Labor Executives’ Assoc.*, 489 U.S. 602, 619 (1989) (*quoting* *Del. v. Prouse*, 440 U.S. 648, 654 (1979)).

¹³³ Lori Andrews, *Body Science*, 83 A.B.A. J. 44-53 (1997).

¹³⁴ *Acton*, 515 U.S. at 661-62.

¹³⁵ *Skinner*, 489 U.S. at 628.

¹³⁶ *Von Raab*, 489 U.S. at 670.

¹³⁷ For instance, the Court has upheld a forced smallpox vaccination in order to promote the health and safety of a larger community. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

attacks.¹³⁸ With regard to the information collected by testing, the issue is not as clear. In previous cases, the court has confronted similar disclosure situations that might impinge on an individual's right to privacy. In *National Treasury Employees Union v. Von Raab*, for instance, the Supreme Court noted as an important condition that only individuals who tested positive for illegal substances had to disclose other related medical information.¹³⁹ Conversely, disclosure of prescription medication was not found to be a significant intrusion into the individuals' privacy right.¹⁴⁰

IV. CONCLUSION

Though genetic testing by employers is not yet widespread, forethought, consideration, and debate about these procedures are now of paramount importance. As with any emerging technology, time will bring increased usage and the eventuality of misuse and abuse. Individuals' and society's interests must be served, with balance established between multiple, complex rights and responsibilities.

Emergence of ethical and legal questions is inevitable and appropriate, and must be addressed. The "shoulds" and "oughts" of ethical debate will be raised time and again with the courts interpreting existing laws, while legislatures inevitably struggle with the utility and challenges of passing more. Ultimately, the courts will determine the acceptable bounds of genetic testing, but laws are not static, being created and interpreted by people who themselves are susceptible to biases, doubts, and changes of mind and heart. These factors, coupled with scientific developments beyond the imagination of most, will maintain genetic assessment and the use of the results at the forefront of attention.

The preceding article introduced a selection of relevant ethical and legal issues and intended to provide others the impetus to weigh and evaluate the topic of genetic testing, vis-à-vis the current legal structure before problems associated with the use and application of this technology become intractable.

¹³⁸ In *Von Raab* and *Acton*, the Court upheld urine collection; in *Skinner*, the Court upheld breathalyzer testing; and in *Rise v. Oregon*, 59 F.3d 1556 (9th Cir. 1995), the Ninth Circuit upheld blood collection against a privacy challenge.

¹³⁹ *Von Raab*, 489 U.S. at 672, n.2.

¹⁴⁰ *Acton*, 515 U.S. at 659-60.