

test for sickle cell trait. ⁿ³ You receive health approval for the job, but are not told that genetic tests were conducted as part of your medical examination. You also are not provided with the test results. By the way, only African American applicants for the job were tested for sickle cell trait, as it is known that this genetic trait is much more prevalent in African Americans.

Now assume you start working in your new clerical job in the laboratory. ⁿ⁴ Months pass and you file a disability claim for a work-related injury in the form of carpal tunnel syndrome. ⁿ⁵ Carpal tunnel syndrome is believed to be caused or exacerbated by repetitive hand or wrist motions. ⁿ⁶ [*81] You assume that your condition was caused by long hours of typing at work on a computer keyboard. Your employer requires you to undergo a physical examination by the company doctor to determine if your condition is work-related. As part of the medical examination, you provide a blood sample. Again you are not told what tests will be performed on the blood sample, but you learn that your blood was tested to determine if you have a genetic condition that involves a deletion on chromosome seventeen. One of your employer's managers requested the genetic test under the mistaken belief that this test would reveal if your genes, rather than the work, caused your carpal tunnel syndrome. You learn about your employer's genetic testing practices from another employee who, during a physical examination related to his disability claim for carpal tunnel syndrome, asked the examining doctor why he was being tested and learned the genetic nature of the test.

Should your new employer have the right to require you to provide genetic information as part of your medical history and to conduct genetic testing as part of a preplacement physical examination or a physical examination related to a work-related disability claim? Should you have the right to be told that genetic tests will be conducted as part of these workplace medical examinations? Do you want to know the results of genetic tests conducted by doctors on behalf of your employer? What are the parameters of permissible uses for genetic information by employers? Should you have legally protected workplace privacy interests in your genetic information? Should some uses of genetic information by your employer be prohibited as unlawful workplace discrimination?

In this article we will address important questions such as these in the context of a comparative **law** study of genetic workplace privacy and non-discrimination in the European Union (EU) and the United States. Advocates of personal data protection and workplace privacy in Europe have reason to be optimistic these days. Broad privacy protections for personal information are now in place throughout the EU. ⁿ⁷ All fifteen countries that [*82] were EU members prior to the recent enlargement of the EU ⁿ⁸ have enacted legislation to implement the personal data protections mandated by the EU's Privacy Directive. ⁿ⁹ This top-down approach, setting basic privacy protections at the EU level through directives that are then adopted through the mechanism of consistent national privacy **laws**, guarantees basic privacy rights to all EU residents regarding the processing of their personal information. ⁿ¹⁰ Momentum is also building for a second round of privacy legislation to further enhance privacy protections for EU residents and to address related discrimination concerns. ⁿ¹¹ This second round of privacy legislation will likely address the need for expanded privacy protections in specific sectors of the economy, including the **employment** sector, and will provide additional protections for sensitive personal information such as genetic data. ⁿ¹² Continued advances in biotechnology and information technology are making genetic information more useful and less expensive as well as easier to access and disclose. ⁿ¹³ It is also likely [*83] that new legislation at the EU level and in the Member States will severely restrict employers' processing of genetic data about employees and prohibit employers from discriminating against applicants and employees on the basis of genetic information. ⁿ¹⁴

Given the global nature of commerce and associated challenges for multinational companies, the time is ripe for new comparative **law** studies examining workplace privacy and nondiscrimination protections related to genetic information. It is true from a broad privacy rights perspective that U.S. privacy **laws**, including those applicable to the workplace, have failed to keep pace with the evolution of basic privacy protections enjoyed by people living in the EU. ⁿ¹⁵ Although privacy protections in the U.S. are found in multiple state and federal **laws**, including constitutions, statutes, common **law** case opinions, administrative **laws**, and even executive orders, this body of **law** does not provide broad privacy and data protection rights for Americans similar to those found in the EU. ⁿ¹⁶ However, in the area of privacy and nondiscrimination **laws** related to genetic information and testing, the U.S. system is poised to provide substantial, if not superior, privacy and nondiscrimination protections for people in the United States. ⁿ¹⁷ As we explain in this article, this is true because the U.S. practice of enacting targeted federal civil rights statutes facilitates adoption of legislation to adequately address privacy and nondiscrimination concerns about genetic information and the workplace.

The U.S. legislative approach for workplace regulation will enable Congress to focus on the workplace and health insurance sectors of the economy where significant privacy and discrimination risks abound. Some relevant federal regulation of the workplace and health insurance markets [*84] is already in place and may be supplemented by specific privacy and nondiscrimination protections for genetic information. For example, the Americans with Disabilities Act (ADA) provides significant privacy and nondiscrimination protections for people with disabilities in the **employment** sector. ⁿ¹⁸ Likewise, the Health Insurance Portability and Accountability Act (HIPAA) regulates patients' medical privacy in the health care sector. ⁿ¹⁹ Legislation has been introduced in Congress to regulate genetic information in the **employment** and insurance sectors. ⁿ²⁰ In February 2005 the Senate passed the Genetic Information Nondiscrimination Act (S. 306). ⁿ²¹ H.R. 1227 was introduced in the House in March 2005 and is currently being discussed in committees. ⁿ²²

Efforts to enact federal legislation regulating the processing of genetic information have been made over the last eight years, but to date, have not passed. ⁿ²³ For example, a bill nearly identical to a previous draft of similar legislation to regulate genetic information was introduced in Congress in 2003. ⁿ²⁴ The proposed Genetic Information Nondiscrimination Act of 2003 passed the Senate unanimously and President Bush supported the legislation. ⁿ²⁵ However, this legislation died in the House without a vote, prompting questions about whether Congress would ever enact legislation [*85] regulating genetic information. ⁿ²⁶ The stage is set for new action by Congress on genetic privacy and nondiscrimination in 2006 now that S. 306 has passed the Senate and H.R. 1227 is pending in the House.

In this article we will provide a comparative analysis of EU and U.S. **laws** concerning workplace privacy and nondiscrimination related to genetic information. The article begins with an overview of genetic information and genetic testing, framing the issues of genetic privacy and nondiscrimination within the larger context of important progress in biotechnology and information technology. The article then provides an overview of pertinent **international law** and lays a foundation for workplace privacy and equality with respect to genetic information. Next the article explores privacy and data protection in the United States, including existing protections for workplace privacy, existing prohibitions on **employment** discrimination based on genetic information, and proposed federal legislation. The article then provides an analysis of workplace privacy and data protection in the EU, including specific protections related to genetic information and genetic testing.

The final section of the article offers a comparative analysis of the U.S. and EU approaches to protecting employees' privacy and prohibiting discrimination based on genetic

information. This section explains why both privacy and nondiscrimination are essential policy goals for legislation relating to genetic information and why effective legislation needs to address both goals simultaneously. We identify several features of the EU vision for protecting genetic information that are constructive to consider as federal legislation develops in the United States. We conclude that the federal legislation pending in the U.S. Congress should be adopted, but offer suggestions for amendments to enhance genetic privacy and nondiscrimination protections for job applicants and employees in the United States. These suggestions draw on insights from studying the European approach to workplace privacy and nondiscrimination. However, we reject the position advocated by the EU's Article 29 Working Party that "all processing of genetic data in the field of **employment** should be prohibited in principle,"ⁿ²⁷ finding this position is both unworkable and undesirable for workplaces in the United States. The approach of the Article 29 Working Party would preclude beneficial uses of genetic data and genetic testing [*86] in the workplace, such as for prevention of occupational exposures that may trigger illnesses in persons with certain genetic predispositions.ⁿ²⁸ As long as strong antidiscrimination provisions with tough enforcement are available in cases where employers misuse genetic information, which we argue the proposed legislation in the United States would provide, an absolute ban on the processing of genetic data and genetic testing is not necessary in the United States. Our suggestions for improvements to the proposed legislation are essential and would enhance already strong antidiscrimination provisions by adding equally strong data privacy protections. This approach is consistent with unique strengths found in the U.S. system of workplace regulation that seeks to protect employees from unfair **employment** discrimination while also favoring targeted and pragmatic solutions that do not unduly interfere with employers' prerogatives to manage the workplace.

II. ADVANCES IN BIOTECHNOLOGY AND INFORMATION TECHNOLOGY PRESENT POLICY CHALLENGES FOR REGULATION OF GENETIC INFORMATION AND TESTING

How is the Human Genome Project related to fair treatment in the work place? According to the recent congressional testimony of Dr. Hudson, Director of the Genetics and Public Policy Center, the Human Genome [*87] Project and related advances in biotechnology are raising important policy concerns about the use of genetic information by employers and others:

[The year 2003] marked the completion of the human genome project, an historic **international** project to decipher, letter by DNA letter, the sequence of all the human genes. I believe that the mapping and sequencing of the human genome is the "moon landing" of the current generation. It is an accomplishment that is stunning in its own right. It also serves as the centerpiece of a wide array of breathtaking breakthroughs in genetics research that have provided new insight into human health and disease. Now these advances are beginning to change the practice of medicine in ways that are at once exciting and challenging. Today I am pleased to discuss the rapid advances in genetic testing and the importance of public policies that will keep pace with the science and will ensure that genetic information is used for benefit and not for harm.ⁿ²⁹

This generation's "moon landing" has impacted our workplaces in ways that were likely not even imagined at the start of the Human Genome Project.ⁿ³⁰ This has prompted legal scholars and policy makers in Europe and the United States to study the social implications and regulatory challenges raised by scientific advances in genetic research.ⁿ³¹ These studies [*88] often focus on the need for new **laws** to protect employee privacy and prevent workplace discrimination related to genetic information.ⁿ³² The literature provides rich background for discussion of genetic privacy and nondiscrimination and provides insights into the answers to important questions: What is genetic information? What is genetic testing? How is genetic information obtained by employers? What is privacy and what privacy interests should applicants and employees have in genetic information about themselves or their families? What is genetic workplace discrimination? How can genetic

information be used for good and not for harm with respect to **employment** decisions and workplace management?

First, what is genetic information? Unlike conventional medical information about an individual, genetic information is a broad term that includes information about an individual as well as the individual's biological family. ⁿ³³ Broadly speaking, information with genetic significance includes the results of tests of genetic material, the results of nongenetic medical tests revealing genetic information, and family medical [*89] history. ⁿ³⁴ Defining genetic information for purposes of regulating genetic privacy and discrimination in the workforce is a challenge. ⁿ³⁵ If defined too broadly, genetic information includes all medical information about the individual and his or her family, losing its genetic focus. ⁿ³⁶ However, if defined too narrowly it excludes information that rightly should be protected as private and not available for employers' use. ⁿ³⁷ The question of what is an appropriate definition of genetic information will be explored more fully in the discussion of proposed federal legislation in the United States and the evolving vision of protections for genetic privacy in the EU. ⁿ³⁸ However, by way of introduction, one state statute defines genetic information as "any written, recorded individually identifiable result of a genetic test . . . or explanation of such a result or family history pertaining to the presence, absence, variation, alteration, or modification of a human gene or genes." ⁿ³⁹

Genetic information also includes information about an individual and the individual's family members that may be sensitive, but is not necessarily medical or health-related. ⁿ⁴⁰ For example, DNA-based genetic tests may reveal genetic information about an individual's biological ancestors or descendants, such as information that confirms or denies parentage or [*90] membership in an ethnic group. ⁿ⁴¹ Also, genetic information may confirm information that is generally obvious about a person, such as the individual's gender, the colors of the individual's skin or eyes, and so on. ⁿ⁴²

Next, what is genetic testing? "Genetic testing involves the analysis of chromosomes, genes and/or gene products to determine whether a mutation is present that is causing or will cause a certain disease or condition." ⁿ⁴³ Genetic tests can reveal three different categories of human conditions:

The first condition is a "disease or defect that is directly attributable to a genetic defect." This condition means that a person tested either has the disease or will develop the disease in the future. The second condition reveals whether a person is a carrier of a particular disease or genetic defect. It is important to note that someone who is a carrier will never develop the disease. Finally, the third condition is a predisposition to developing the disease. Under the third condition, the individual is "asymptomatic" and may never develop the disease, but the person is susceptible to developing the disease. ⁿ⁴⁴

In the workplace context, genetic testing can be implemented in two basic forms: screening and monitoring. ⁿ⁴⁵ Genetic screening involves predictive genetic examinations or the examination of an individual's genetic code in order to determine if that individual may be prone to disease or even to certain behaviors such as laziness, violence, depression, alcoholism, and so on. ⁿ⁴⁶ What [*91] is sometimes misunderstood, however, is that most of human behavior and disease are not the result of a single mutation or gene, but instead "the culmination of lifelong interactions between our genome and the environment." ⁿ⁴⁷ In most cases current scientific knowledge does not provide a clear link between an individual's genetic sequence and that person's likelihood of developing disease or undesirable personality traits. ⁿ⁴⁸ Therefore any conclusions regarding the longevity and quality of an employee's tenure based on analysis of genetic data in this regard may be speculative at best.

Unlike genetic screening, genetic monitoring is potentially useful to the person monitored. It involves testing over time to assess if an individual's genetic structure has been altered or

damaged due to exposure to certain risks. ⁿ⁴⁹ In the **employment** context this might involve monitoring employees to determine if their exposure to a hazardous environment (due to chemical or other toxin exposure) is adversely affecting their health, and whether a change of position should be made as a result. ⁿ⁵⁰ This is a legitimate use of genetic testing because the objective of monitoring is the prevention, detection, and response to occupational disease. However, there is still a danger to employees that without appropriate legal safeguards employers will use these and genetic screening tests to discriminate against employees.

Looking more closely at the distinction between screening and monitoring, a genetic screen is a one-time test "to determine whether an employee or an applicant has a genetic condition that would predispose him or her to developing a particular disease or a genetic defect that could be transmitted to offspring." ⁿ⁵¹ For example, alpha-1-antitrypsin deficiency is a genetic condition that could be detected by a genetic screen and indicates genetic predisposition toward some lung diseases. ⁿ⁵² As such, alpha-1-antitrypsin deficiency is a genetic trait that appears to be relevant to some [*92] job placement decisions, such as placement in jobs involving occupational exposures in the form of coal dust, asbestos, or even cigarette smoke that may lead to, or exacerbate, lung diseases. ⁿ⁵³ A genetic screen allows employers to identify individuals who are "hypersusceptible" to occupational illnesses or to identify employees who are predisposed to nonoccupational diseases. ⁿ⁵⁴ In contrast, genetic monitoring is generally used for a group of employees rather than an individual applicant or employee. ⁿ⁵⁵ Genetic monitoring focuses on monitoring employees to determine if occupational exposure to hazardous agents has caused chromosomal or genetic damage, as opposed to whether an individual possesses a particular genetic trait. ⁿ⁵⁶ For example, an employer could study tumor cells from employees who have developed tumors to determine if genetic defects are present in the tumor cells. ⁿ⁵⁷ Such monitoring could provide relevant information about occupational exposures and risks of contracting disease when there are known or likely environmental causes of tumors. ⁿ⁵⁸

Currently there are over 1000 genetic tests available or in development. ⁿ⁵⁹ These tests range from tests for fatal and untreatable diseases, such as Tay Sachs disease, to tests for gene mutations that increase the risk [*93] of developing a disease at some point in the future, such as the BRCA1 and BRCA2 mutations that are associated with an increased risk of breast and ovarian cancer. ⁿ⁶⁰ However, the availability of genetic testing has outpaced development of effective treatments of genetic diseases:

The information to be gained from genetic testing is incredibly powerful and can lead to life altering decisions that improve health and the quality of life. But it is important to remember that our ability to detect gene misspellings precedes, sometimes by decades, the development of effective prevention and treatment. For example, we have had a genetic test for Huntington disease for over a decade but still have no effective intervention. ⁿ⁶¹

Further, the medical community and the literature recognize significant limitations on the use of genetic testing to predict that an asymptomatic individual with a genetic trait or mutation will develop an associated condition or disease. ⁿ⁶² An individual's genetic profile has been characterized as a "future diary" that has come to be seen as holding everything that an individual is or will become. ⁿ⁶³ However, at best the diary is probabilistic; it does not take into account environmental factors that may be more determinative than genetic factors. ⁿ⁶⁴ Use of a person's genetic profile to predict his or her future health is limited due to the uncertainty of disease manifestation: some genetic diseases are complex and genetic tests do not predict the severity of the disease. ⁿ⁶⁵ Other genetic diseases are multifactorial, requiring the interplay of multiple genes and/or environmental factors before the disease will manifest. ⁿ⁶⁶ Genetic test results may be [*94] misinterpreted by medical personnel due to reasons such as lack of training and shortage of personnel. ⁿ⁶⁷ Additionally, the testing technology has limitations. For example, some genetic tests do not give accurate

test results because the tests may produce too many false positives or fail to detect the genetic trait being tested. ⁿ⁶⁸ Beyond the limitations of using genetic information to predict the future health of individuals is the realization that most employers and other public and private bodies are not in a position to fairly use and interpret genetic information because they lack specific knowledge and professional training. ⁿ⁶⁹ Consequently, in order to use genetic information appropriately in **employment** decisions when genetic information is relevant to **employment** decisions, employers must rely on the expertise and advice of medical professionals who are qualified and entitled to carry out genetic tests and/or to interpret genetic information. ⁿ⁷⁰

How do employers obtain genetic information? There are four primary ways for employers to obtain genetic information about an individual applicant or employee: (1) perform a genetic test related to the individual; (2) require an individual to release his or her medical records or provide medical history that contain genetic information; (3) use genetic information that is otherwise available about the individual, such as genetic information available in computerized databases that store health records about the individual or health insurance claim forms; and (4) use genetic information that is otherwise available related to the individual's biological family, such as records about the prevalence of genetic diseases in the individual's family. ⁿ⁷¹ The use of genetic testing as part of routine physical examinations is becoming increasingly likely as the cost decreases and more genetic tests become available. ⁿ⁷²

[*95] What is privacy and what privacy concerns are related to workplace use of genetic information about applicants or employees? Privacy scholars have identified several privacy-related interests of employees and applicants in this context. The European perspective, and arguably the **international** perspective, begins with recognizing the right to privacy as a fundamental human right that is "solidly embedded in **international** human rights **law** as well as in national constitutions, legislation and juris-prudence." ⁿ⁷³ In Europe, privacy rights related to genetic information [*96] and testing build on the concept of individual freedom to "act in accordance with their own feelings, will and personality." ⁿ⁷⁴ The zone of individual privacy can be divided into physical and informational zones of privacy. ⁿ⁷⁵ The physical zone involves respect for a person's physical integrity, home, and correspondence. ⁿ⁷⁶ Informational privacy protects against the unauthorized collection, storage, use, and disclosure of personal information. ⁿ⁷⁷ The EU Privacy Directive and privacy legislation adopted in the Member States consistent with the Directive protect individual privacy. ⁿ⁷⁸ It is clear that employees in workplaces in Europe have rights to privacy. ⁿ⁷⁹

In contrast, outside the context of constitutional privacy rights of individuals with respect to government intrusions, ⁿ⁸⁰ individual privacy rights in the United States are not based on a concept of fundamental rights. American notions of privacy are reflected in the concept of "rugged individualism." ⁿ⁸¹ Individual autonomy and liberty are revered, as is apparent in the jurisprudence of decisional privacy. ⁿ⁸² However, the right to privacy in private workplaces is treated as akin to personal property. ⁿ⁸³ [*97] As such, it may be bargained with and exchanged for other rights and privileges, including those obtained in an **employment** relationship. ⁿ⁸⁴ In other words, because privacy belongs to the individual, it may be traded away by the individual in exchange for something of commensurate value, such as a job. Compared to employees in the EU, it is much less clear that U.S. employees have any significant privacy rights in private-sector workplaces.

U.S. **law** in this area stands apart from most of the world, which starts instead from the position that the right to privacy is a central tenet of human dignity. ⁿ⁸⁵ Human dignity means "being accorded the respect and status appropriate to a human being, being treated in a way that allows or enables one to live a becoming existence." ⁿ⁸⁶ Unlike proprietary

privacy rights, human dignity is not generated by the individual, but is instead created by one's community and bestowed upon the individual. ⁿ⁸⁷ It cannot therefore be bartered away or exchanged under traditional notions of at-will **employment** and contract **law** as seen in U.S. **law**. ⁿ⁸⁸

[*98] In the specific context of genetic information and testing, the privacy rights of individuals are said to include individual rights of autonomy and confidentiality related to sensitive information. For example, individual autonomy, or the individual's freedom to make his or her own decisions without external control, is a privacy concern that arises with respect to whether an individual wants to undergo genetic testing. ⁿ⁸⁹ Included in autonomy is the right to be provided with reasonable information about the genetic tests to be administered and the right to make a voluntary decision whether to undergo the tests. ⁿ⁹⁰ There also may be a privacy right "not to know" the test results, particularly if medical science offers no beneficial treatment for a person who has a risk of developing a genetic disease in the future. ⁿ⁹¹ Because genetic information may be sensitive and access to that information is a privacy concern, individuals also may be concerned with the confidentiality of information produced by genetic testing. ⁿ⁹² The privacy concerns about confidentiality of genetic information have been characterized as "informational privacy." ⁿ⁹³

What is genetic workplace discrimination? Genetic discrimination can be defined as the discrimination that is directed toward an individual or a member of an individual's family solely on the basis of that individual's [*99] genotype. ⁿ⁹⁴ Advances in genetic science, including the science of genetic testing, provide opportunities for employers to use genetic information either for "good or for harm" with respect to workplace management. ⁿ⁹⁵ Broadly speaking, unfair discrimination related to an individual's genotype is certainly a use for harm. ⁿ⁹⁶ Potential uses of genetic information and genetic testing for "good" include protecting the health and safety of employees on the job. ⁿ⁹⁷ More controversial is whether employers should be permitted to use genetic information to minimize employer costs and liabilities associated with hiring employees who are unfit for the job. ⁿ⁹⁸ Potential cost minimization advantages for employers may relate to liability under occupational safety and health **laws**, workers' compensation **laws**, as well as tort liability for injuries to third persons by employees under negligent hiring, retention, or entrustment theories. ⁿ⁹⁹ [*100] Potentially harmful uses of genetic information and genetic testing in the workplace may lead to "alarming consequences" such as: creation of a genetic underclass, the violation of individual privacy rights, decreases in safety in the workplace, and the use of genetic discrimination as a pretext for other forms of discrimination. ⁿ¹⁰⁰

When discussing the need for prohibitions of workplace discrimination based on genetic information and testing, one threshold issue is whether to limit the analysis to concerns about protecting individuals who are asymptomatic for genetic disease: "The quintessential feature of genetic discrimination is the use of genetic information about an asymptomatic person. If the disorder related to a genetic characteristic has occurred, discrimination based on the disorder may be unfair but is not customarily considered genetic discrimination." ⁿ¹⁰¹ On the other hand, **laws** protecting persons with disabilities may prohibit discrimination against some people with genetic disorders by treating genetic disorders as forms of disability. ⁿ¹⁰² The scope of our discussion in this article of workplace discrimination **laws** and genetic discrimination will be limited to protection for applicants and employees who are asymptomatic for genetic disease. In this context the article will discuss the protections afforded asymptomatic persons by federal **laws**, such as the ADA, but also have broader application to other disabled persons such as those with diagnosed genetic disorders.

III. OVERVIEW OF PRIVACY AND EQUALITY PRINCIPLES RELATED TO GENETIC PRIVACY AND NONDISCRIMINATION FROM APPLICABLE INTERNATIONAL LAW

So far in this article, we have focused on genetic privacy issues in the United States and in the EU. However, genetic privacy in the workplace [*101] triggers the application of universal human rights standards that transcend national or regional state boundaries. Indeed, as is explained in the sections below, the rights in issue are not conferred upon individuals by States, but rather are considered to inhere in every individual by virtue of their humanity. The question then turns to the obligation of States to respect those fundamental human rights and ensure as far as possible that private actors, such as employers, also respect those rights.

*A. Foundational Concepts of Privacy, Equality, and Nondiscrimination from **International Human Rights Law***

The rights to privacy, equality, and nondiscrimination are protected by **international human rights law** and are germane to any discussion of protecting genetic information. Protecting human dignity is the central tenet of the **international** human rights framework. Following the atrocities of World War II, the **international** community drafted the United Nations Charter (U.N. Charter), which enshrines the notion of human dignity, ⁿ¹⁰³ followed in 1948 by the Universal Declaration of Human Rights (UDHR), which states in its preamble that:

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world. . . . Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom; ⁿ¹⁰⁴

and enshrines in Article 1 the concept of human dignity and equality: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood;" ⁿ¹⁰⁵ and the rights to equality and nondiscrimination in Article 2: "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, [*102] color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status . . . ; ⁿ¹⁰⁶ and in Article 7: "All are equal before the **law** and are entitled without any discrimination to equal protection of the **law**. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination." ⁿ¹⁰⁷

In addition to the protection of these rights in the UDHR, the rights are also protected in the two **international** covenants: the **International** Covenant on Civil and Political Rights (ICCPR); ⁿ¹⁰⁸ and the **International** Covenant on Economic, Social, and Cultural Rights. ⁿ¹⁰⁹ Both [*103] of these covenants recognize that the rights to privacy, equality, and nondiscrimination "derive from the inherent dignity of the human person." ⁿ¹¹⁰ Together these three instruments form the **International** Bill of Rights.

Genetic data is obtained from human beings and inherently necessitates an invasion (consensual or not) into the human body to obtain this information and the possibility that this information may be used to affect an individual's enjoyment of other rights. In other words, the rights to privacy (in terms of obtaining the information, consent, and use of the information, including the right of an individual not to know the results) and the rights to equality and nondiscrimination (inequality and discrimination may result from how the genetic data is used) are triggered.

The rights to privacy, equality, and nondiscrimination have evolved over the years to enable an encompassing approach to genetic privacy issues. While the concept of human dignity

informs any discussion of human rights, it is important to note that **international** human rights **law** exists to ensure the promotion and protection of distinct legal rights (i.e., rights to privacy, equality, and nondiscrimination) -- in some cases without derogation.

[*104] 1. Privacy

Privacy rights are guaranteed in **international** human rights **law** ⁿ¹¹¹ and in regional instruments. ⁿ¹¹² The understanding of what is entailed in the right to privacy has evolved over the years to include not only privacy rights in one's own home or to one's own correspondence, for example, but to broadly encompass the right to control one's life to the extent that one is free from physical intrusion and has control over one's personal information including health or genetic information. ⁿ¹¹³ In this regard Article 17 of [*105] the ICCPR imposes an obligation on States to ensure that this right is protected and afforded to individuals by the State as well as by private citizens. ⁿ¹¹⁴ The Human Rights Committee has also reaffirmed the positive obligation on States to ensure that Article 17 rights in the ICCPR are "guaranteed against all such interferences and attacks whether they emanate from State authorities or from natural or legal persons," and therefore States must "adopt legislative and other measures to give effect to the prohibition against such interferences and attacks as well as to the protection of this right." ⁿ¹¹⁵ European jurisprudence on privacy relating to health information ⁿ¹¹⁶ clearly sets out the individual's right to consent to the [*106] obtaining and use of the information, which is of course relevant to the discussion of genetic information. The European Convention also sets out positive obligations on the States to respect the privacy and family life rights contained in Article 8. ⁿ¹¹⁷

2. Equality and Nondiscrimination

The rights to equality and nondiscrimination are intertwined and anchor the framework of **international** human rights **law**. ⁿ¹¹⁸ In essence, these [*107] rights ensure that all human beings are afforded universal human rights equally and without discrimination on enumerated grounds, and are afforded equal protection under the **law** without discrimination. The use of the phrase "any other grounds" in antidiscrimination rights guarantees has been interpreted to mean that the list is not exhaustive. These grounds also reveal, though, that in some cases discrimination with a clear and cogent reason will be permitted. For example, denial of the right to vote to minors is not viewed as discrimination. ⁿ¹¹⁹

Finally, it is also worth noting that the **International** Labour Convention (ILO) No. 111 Concerning Discrimination in Respect of **Employment** and Occupation, ⁿ¹²⁰ which proscribes any discrimination in the workplace, [*108] would of course be relevant to any use of genetic information to discriminate in the workplace.

*B. **International** Efforts to Regulate Privacy and Nondiscrimination of Genetic Information*

The **international** community has also recognized the need to regulate the use of genetic information, specifically to protect the rights to privacy, equality, and nondiscrimination. In 1997, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) ⁿ¹²¹ passed the Universal [*109] Declaration on the Human Genome and Human Rights (UNESCO Declaration). Article 6 of the UNESCO Declaration provides: "No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity." ⁿ¹²² Other rights protected in the UNESCO Declaration ⁿ¹²³ include the need for informed [*110]

consent, ⁿ¹²⁴ the right of an individual to know about the results of genetic testing, ⁿ¹²⁵ and the right to confidentiality of genetic information. ⁿ¹²⁶

The UNESCO **International** Declaration on Human Genetic Data ⁿ¹²⁷ provides additional principles ⁿ¹²⁸ to guide the collection and use of genetic [*111] information. ⁿ¹²⁹ Article 14 sets out the right of an individual to privacy and confidentiality. ⁿ¹³⁰

[*112] In addition to these, UNESCO ⁿ¹³¹ has also established the **International** Bioethics Committee ⁿ¹³² and the Intergovernmental Bioethics Committee, ⁿ¹³³ which work together to focus on the legal and ethical issues [*113] related to life sciences, and in particular, to disseminate the principles and flesh out the issues deriving from the principles contained in the Universal Declaration on the Human Genome and Human Rights.

In February 2005, the **International** Bioethics Committee completed its Preliminary Draft on Universal Norms on Bioethics (Draft Universal Norms). ⁿ¹³⁴ The Explanatory Memorandum for the Draft Universal Norms (Explanatory Memorandum) is particularly helpful in providing insight into those issues noted as important by the framers. Article 4 of the memorandum, entitled Human Rights and Dignity, hails the importance of protecting rights and respecting human dignity in the collection of genetic information. ⁿ¹³⁵ Article 6 ⁿ¹³⁶ refers to the protection of equality rights and Article 8 ⁿ¹³⁷ to nondiscrimination and nonstigmatization. Article 9 refers to personal autonomy and individual responsibility, a hallmark of human [*114] dignity, which "is directly derived from binding **international** human rights law." ⁿ¹³⁸

The Explanatory Memorandum, while not binding in any manner, encapsulates the current **international** thinking on genetic information and **international** human rights including privacy, equality, and nondiscrimination. It is encouraging in that the framers clearly see that **international** human rights law protections afforded to individuals must be implemented. The Explanatory Memorandum reaffirms that **international** human rights law provides specific rights that must be protected. These rights should not be obfuscated in discussions of human dignity, but rather, should be recognized as legally enforceable rights that operate holistically and include in their guarantees the respect for human dignity. Otherwise, there is a danger that the infringement of rights might occur while lip service is paid to human dignity. ⁿ¹³⁹

[*115] *C. EU Regional Efforts to Regulate Privacy and Nondiscrimination of Genetic Information*

At the regional level, the most important instrument is the European Convention on Human Rights and Biomedicine (EU Convention), passed in 1997 by the Council of Europe to legislatively proscribe genetic discrimination. ⁿ¹⁴⁰ Article 1 of the EU Convention specifically upholds human dignity and human rights without discrimination:

Article 1 -- Purpose and Object

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine. Each Party shall take in its internal law the necessary measures to give effect to the provisions of this Convention.

Unlike the UNESCO and ILO instruments, ⁿ¹⁴¹ the EU Convention "is the first legally binding **international** text designed to preserve human dignity, rights and freedoms through a series of principles and prohibitions against the misuse of biological and medical advances." ⁿ¹⁴² The EU Convention proscribes any form of discrimination against individuals on the grounds of their genetic inheritance and recognizes the need to respect the uniqueness and

diversity of every individual. ⁿ¹⁴³ An EU Presidency Statement [*116] from 2001 encapsulates the EU's approach to genetic information and protecting the rights of individuals:

Genetic discrimination warrants special consideration because it comes at the intersection between two basic human rights: the right to privacy and the right to protection from any form of discrimination. One major ethical issue concerns respect for confidentiality and privacy, since genetic testing reveals the most intimate details of a human being's physical and even psychological determinants. What is more, the information does not only affect that individual, but also involves members of the person's nuclear or extended family (relatives), as well as future generations. The European Union is also very much aware of the risks of "preventive discrimination," particularly in matters of health, insurability and employability, as now made possible by scientific and technological progress. Genetic testing is currently confined to screening for certain diseases such as breast and colon cancer, or diabetes, but is set to become increasingly common and so a lead needs to be given before unacceptable practices become established. ⁿ¹⁴⁴

In sum, **international** human rights **law** creates binding obligations upon States which have ratified treaties. ⁿ¹⁴⁵ Accordingly, where the United States or EU Member States have ratified the relevant **international law** treaties, [*117] they are obligated to ensure that the treaties are implemented in their domestic **laws**. ⁿ¹⁴⁶ Unlike positive **law** approaches typically found in domestic legal frameworks that use legitimate coercion, **international** human rights **laws** seek to change norms and values through a constructive approach. ⁿ¹⁴⁷ The discussion of workplace genetic privacy invokes the **international** human rights **law** guarantees of privacy, equality, and nondiscrimination. Any domestic or regional efforts to regulate this matter would therefore benefit from: (a) ensuring compliance with binding **international law** obligations and (b) reaping the wealth of interpretation on these rights that has evolved over the years. Given the nature of **employment** in the globalized world, transborder **employment** is common. An internationalized approach to workplace genetic privacy and nondiscrimination would significantly further **international** harmonization and would ensure the implementation of fundamental **international** human rights.

[*118] **IV. THE UNIQUE U.S. APPROACH TO GENETIC PRIVACY AND NONDISCRIMINATION IN THE WORKPLACE**

Relatively speaking, U.S. employees in the private sector have minimal privacy protections for personal information gathered by their employers, including genetic information and other medical or health-related personal information. ⁿ¹⁴⁸ In this section we examine U.S. privacy protections for employees in private-sector workplaces with a focus on federal legislation. ⁿ¹⁴⁹ We also examine proposed federal legislation passed by the Senate and pending in the House to protect employees' privacy in their genetic information, restrict genetic testing in the workplace, and prohibit **employment** discrimination related to genetic information.

*A. Overview of U.S. Privacy **Laws***

Unlike the EU Privacy Directive, U.S. **law** does not create a broad right to informational privacy that protects employees' personal information from prying by employers or regulates unfair use of employees' personal information in **employment** decisions. ⁿ¹⁵⁰ Broad privacy theories found in U.S. tort **law** [*119] do apply to the workplace. ⁿ¹⁵¹ However, no reported court opinions have directly addressed the potential tort liability of employers related to privacy issues involving employees' genetic information in private-sector workplaces. ⁿ¹⁵²

A few reported privacy tort cases involving sensitive medical information give us insight into how courts may resolve privacy issues related to genetic information in the context of

private-sector workplaces. For example, a court in a privacy tort case found individuals have privacy interests in sensitive personal information about themselves that can be obtained by others through medical tests. In *Doe v. High-Tech Institute, Inc.*, High-Tech Institute obtained consent from one of its students to test his blood for rubella, but then the school performed an additional test without the student's consent to confirm that the student had the human immunodeficiency virus (HIV).ⁿ¹⁵³ After obtaining the student's test results, High-Tech Institute disclosed the student's HIV-positive status to a government department of health.ⁿ¹⁵⁴ The Colorado Court of Appeals held the student had two separate causes of action against High-Tech that were grounded in privacy tort **law**. First, he had a cause of action for unreasonable intrusion into his seclusion based on allegations that High-Tech conducted unauthorized medical tests on his bodily fluids.ⁿ¹⁵⁵ Second, he had a cause of [*120] action for impermissible public disclosure of private facts based on allegations that High-Tech disclosed his HIV test results to a government agency.ⁿ¹⁵⁶ Because these two torts are separate infringements of an individual's privacy rights, *Doe* held the student had two separate causes of action in tort against High-Tech Institute.ⁿ¹⁵⁷

A second case arising in the public **employment** context provides insight into privacy claims related to genetic testing and other medical tests for sensitive personal information. In *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*, the Ninth Circuit held that a person has a constitutional right of privacy in his or her genetic information and other sensitive personal information that restricts unauthorized testing of bodily fluids for **employment** purposes.ⁿ¹⁵⁸ Because this case involved testing of government employees, constitutional privacy rights were involved as opposed to common **law** tort liability.ⁿ¹⁵⁹ The Ninth Circuit analyzed the sensitive nature of genetic and other personal medical information revealed through the employer's tests of employees' blood and urine for pregnancy, sickle-cell trait, and syphilis.ⁿ¹⁶⁰ The court [*121] noted that genetic tests for sickle cell trait may reveal sensitive information about family history and implications for reproductive decision making; likewise medical tests for pregnancy and syphilis also may reveal sensitive information about one's sexual history.ⁿ¹⁶¹ The Ninth Circuit held giving one's consent "to a general medical examination does not abolish one's privacy right not to be tested for intimate, personal matters involving one's health -- nor does consenting to giving blood or urine samples, or filling out a questionnaire."ⁿ¹⁶²

In the health care industry, a general duty of a health care provider to preserve medical confidences exists under tort **law** that provides privacy protection for unauthorized disclosures of medical records including genetic information.ⁿ¹⁶³ However, the duty to preserve confidences does not arise unless a special confidential relationship exists between the person conducting the tests and the person tested, as between physician and patient, and does not ordinarily apply to employer/employee relationships.ⁿ¹⁶⁴

In short, U.S. privacy **law** does not recognize a broad privacy interest in employees' personal information that would encompass employees' genetic information except in limited circumstances related to specific types of disability-related information that are discussed in the next section.ⁿ¹⁶⁵ Generally speaking, employers may avoid common **law** tort liability by following reasonable practices with respect to protecting the confidentiality of medical information, obtaining consent before conducting genetic tests, and making sure any collection of genetic information and/or testing is only for job-related purposes. Where an employer complies with ADA and HIPAA regulations before collecting or using medical information about applicants and employees, [*122] and follows the medical confidentiality rules contained in these regulations, it should have little difficulty avoiding common **law** privacy tort liability. For example, with respect to the tort of intrusion into seclusion, employers can generally avoid liability for unreasonable intrusions by reducing employees' expectations of privacy. Privacy expectations can be reduced by disclosing the nature of

tests to be conducted and obtaining consent from the person to be tested for the testing. With respect to the tort of unreasonable publication of private facts, compliance with ADA medical confidentiality regulations will likely prevent the type of public disclosure of private medical information that this tort encompasses and thereby minimize employers' liability.

B. Federal Statutes Regulating Genetic Privacy and Discrimination in the Workplace

The primary source of federal **law** that requires employers to protect the privacy of medical information related to employees is the ADA. ⁿ¹⁶⁶ The ADA applies to all private-sector employers with more than fifteen employees and prohibits disability discrimination by a covered employer with respect to all **employment** practices and policies. ⁿ¹⁶⁷ The ADA prohibits disability discrimination against applicants and employees who fit within a three-prong definition of disability encompassing those who currently have a disability, those who are regarded by their employer as having a disability, and those who have a medical record of having had a disability. ⁿ¹⁶⁸ The ADA has significantly influenced human resources practices by creating minimum standards for medical inquiries, medical examinations, and confidentiality of medical information applicable to all applicants and employees of a covered employer. ⁿ¹⁶⁹ Arguably, employers' compliance [*123] with these standards has improved workplace privacy for all employees, even for employees who do not have disabilities as defined by the ADA.

The statutory language of the ADA does not expressly cover genetic information and genetic testing. ⁿ¹⁷⁰ However the Equal **Employment** Opportunity Commission (EEOC), the federal administrative agency that enforces the ADA, interprets the ADA's disability discrimination protections to apply to the use of genetic information and genetic testing for **employment** purposes. ⁿ¹⁷¹ The EEOC has been involved in high-profile enforcement actions related to pre-**employment** genetic testing, including litigation of ADA claims against the Burlington Northern Santa Fe Railway. ⁿ¹⁷² Because the ADA applies to all workplace practices and policies, it [*124] arguably applies to the employers' use and collection of genetic information that is a form of sensitive medical information. ⁿ¹⁷³ However, not all genetic information is medical information -- genetic information may instead relate to sensitive characteristics such as gender, race, or parentage. ⁿ¹⁷⁴ Consequently, this discussion of the applicability of the ADA to genetic information is limited to genetic information that is also medical information.

The ADA limits employers' prerogatives related to genetic testing for **employment** purposes, because most if not all genetic tests will be medical tests covered by the ADA's medical examination rules. ⁿ¹⁷⁵ For example, scientists are continuing to develop new genetic testing applications with the potential to help employers select employees for jobs who are genetically more likely to perform well on the job. ⁿ¹⁷⁶ In the not too distant future, genetic tests may even help employers scientifically predict a person's [*125] personality traits in the employee selection process, replacing current practices related to personality testing of job applicants. ⁿ¹⁷⁷ These genetic tests will likely be covered by the ADA's rules on medical examinations and medical inquiries because medical professionals conduct the tests. To the extent that genetic tests reveal medical information, the ADA's medical confidentiality rules will also apply.

The ADA provides comprehensive privacy protections for applicants and employees related to personal data when that personal information is in the form of medical information. ⁿ¹⁷⁸ In this regard the ADA is similar to the EU Privacy Directive, which protects employee medical information as a form of personal data. ⁿ¹⁷⁹ The ADA does this by requiring employers to treat applicants' and employees' medical information as confidential, including obligations to keep the information secure and not to disclose the information except in very limited

circumstances. ⁿ¹⁸⁰ The medical confidentiality rules appear to apply to employers' processing and retention of all employees' medical information -- whether or not the employee has a medical condition that constitutes a disability within the meaning of the ADA. ⁿ¹⁸¹ However, as discussed later in this article, the broad scope of the ADA's medical confidentiality rules does not necessarily mean that it creates enforceable [*126] privacy rights for all employees because nondisabled persons have no statutory remedy for violations of the ADA's medical confidentiality rules. ⁿ¹⁸² In addition to limiting the use and retention of medical information, the ADA also limits collection of medical information. It protects the privacy of applicants by preventing the employer from requiring disclosure of medical information or medical examinations from applicants before a certain point in the sequence of the hiring process and enables applicants to keep their medical information private before that point:

The ADA . . . prohibit[s] medical examinations and inquiries until *after* the employer has made a real job offer to the applicant. [For a job offer to be real] an employer must have either completed all non-medical components of its application process or be able to demonstrate that it could not reasonably have done so before issuing the offer. . . . The ADAH . . . deliberately allow[s] job applicants to shield their private medical information until they know that, absent an inability to meet the medical requirements, they will be hired, and that if they are not hired, the true reason for the employer's decision will be transparent. ⁿ¹⁸³

The ADA's regulation of the hiring sequence creates different sets of rules for collecting medical information that depend on whether the employer's collection pertains to: (1) an applicant who has not yet received a job offer [*127] (pre-offer), (2) an applicant who has received a job offer (post-offer), or (3) an employee who is no longer an applicant (during **employment**). ⁿ¹⁸⁴

At the pre-offer stage before a job applicant has received an offer of **employment**, the ADA prohibits medical examinations and prohibits collection of any medical information about the applicant that is a "disability related inquiry." ⁿ¹⁸⁵ This prohibition on medical examinations and collection of medical information about applicants protects applicants' privacy while applicants are being considered for **employment** and prior to receiving a job offer. ⁿ¹⁸⁶

At the post-offer stage, after an applicant has received a job offer that may be conditioned only upon determination that the applicant is able to perform essential job functions, the employer is free to conduct medical examinations of the employer's choice and to collect all forms of medical information about the applicant. ⁿ¹⁸⁷ At this stage the employer may gather all forms of medical information about the applicant who has received a job offer, including genetic information, even if the medical information collected is not job-related. ⁿ¹⁸⁸ This means that the ADA does not restrict an employer's ability to conduct post-offer medical examinations that include genetic tests, although some state **laws** may restrict or prohibit use of genetic testing in this context. ⁿ¹⁸⁹ It is unlawful to revoke a job offer based on [*128] disability-related medical information if the applicant is able to perform essential job functions. ⁿ¹⁹⁰ Under the ADA it is also unlawful to fail to make reasonable accommodations for an applicant's disability when those accommodations would enable the applicant to perform essential job functions. ⁿ¹⁹¹

In the third stage after **employment** begins, the ADA restricts the employer's ability to collect medical information about employees and to require employees to submit to medical examinations. ⁿ¹⁹² Employers can only collect employees' medical information if it constitutes "disability related information," when it is job-related. ⁿ¹⁹³ The EEOC interprets this restriction to include "asking about an employee's genetic information." ⁿ¹⁹⁴ So, it is lawful under the ADA for an employer to require genetic tests as part of workplace-related medical examinations if the tests are jobrelated. ⁿ¹⁹⁵

Once medical information is lawfully collected under the ADA, use and disclosure of the information is further regulated. In all three of the [*129] stages of the **employment** relationship, the ADA prohibits the employer from using and disclosing applicants' and employees' medical information except for job-related reasons and limits the categories of persons who may receive confidential medical information. ⁿ¹⁹⁶

Viewed from a personal data protection perspective, the ADA addresses concerns of privacy related to applicants' and employees' medical information and restricts processing employees' and applicants' medical information including genetic information. Employees have more data protection than applicants, because applicants have no privacy protection from medical examinations or inquiries by their employers in the interval between receiving job offers and becoming employees. Details of applicants' or employees' medical history or medical conditions are often not job-related, yet employers are free to inquire into all medical information after making job offers and before **employment** begins. Although applicants who have job offers receive no privacy protection under the ADA from employers who choose to pry into sensitive medical information, they are protected from disability discrimination if their employers' use disability-related medical information that is not job-related in a discriminatory manner. Employees receive more privacy protections under the ADA, because the ADA generally prohibits employers from prying into employees' medical conditions beyond assessing the ability to perform job functions, need for accommodation, or need for time away from work. Employees also receive protection from disability discrimination, but the risk of unfair treatment based on genetic information for employees may be lower than for applicants because the employer simply is not permitted to obtain private medical information that is not job-related. Family medical leave **laws** also restrict the amount of information that an employer may request from an employee or an employee's doctor [*130] to substantiate an employee's leave request, and further require employers to keep confidential an employee's medical reasons for taking family medical leave. ⁿ¹⁹⁷

One major weakness of the ADA's privacy and nondiscrimination protections is that some genetic information may not rise to the level of ADA protection, and therefore use of this type of genetic information will not be covered by the ADA's nondiscrimination provisions. For example, would it be lawful under the ADA for an employer to use genetic information about an applicant that relates to the applicant's predisposition for a disabling disease, like breast cancer, as the basis for withdrawing a conditional offer of **employment**? The EEOC takes the position that it would be unlawful for the employer to withdraw a conditional offer of **employment** in these circumstances because a person who has a genetic predisposition to breast cancer would be protected as a disabled person by the ADA. ⁿ¹⁹⁸

But is this result necessarily true? As discussed earlier in this article, the statutory language of the ADA does not expressly address genetic information or genetic discrimination. So, unless Congress enacts legislation prohibiting this type of unfair **employment** action, ultimately it will be up to the courts to decide whether the ADA covers genetic discrimination and to what extent genetic information is covered by the ADA's medical confidentiality rules and medical examination rules. When the U.S. Supreme Court recently decided a trilogy of ADA cases involving the scope of the ADA, it severely limited the scope of the ADA. The Court held persons whose physical or mental impairments were correctable through medical treatment and other means were not protected by the ADA. ⁿ¹⁹⁹ The applicants and employees in these cases were all treated adversely by employers based on their physical impairments, yet they were not covered by the ADA [*131] and had no remedy under the ADA. ⁿ²⁰⁰ For example, two applicants with severe vision impairments were not covered by the ADA because they wore glasses with corrective lenses that improved their vision to the level of persons without such impairments. ⁿ²⁰¹ However,

because corrective lenses rendered the applicants not covered by the ADA, there was no violation of the ADA when the employer refused to consider them for jobs as pilots on the basis that their uncorrected vision without glasses was inadequate. ⁿ²⁰²

The Supreme Court has not yet considered a case involving whether the ADA covers genetic testing or covers people treated adversely by their employers due to genetic information. When cases involving genetic discrimination in the workplace come before the courts, the courts will apply the rules set out in recent Supreme Court cases. As a result, like the plaintiffs in recent cases, many vulnerable persons are likely to find they are not sufficiently impaired to be covered by the ADA. ⁿ²⁰³ So, even an applicant or employee who has a genetic predisposition to a serious disease, like breast cancer, may not be covered by the ADA -- yet, under the rationale of recent Supreme Court cases, use of this genetic information for **employment** purposes would not be prohibited by the ADA. ⁿ²⁰⁴ Because the ADA only [*132] prohibits disability discrimination, and the definition of covered persons is statutorily limited to those with substantially limiting impairments, those with records of such impairments, and those regarded as having substantially limiting impairments, **employment** action against a person with a medical condition or genetic profile that falls short of this definition is not covered by the ADA. ⁿ²⁰⁵ For this reason there is no remedy under the ADA for violation of the medical inquiry, medical examination, or medical confidentiality rules by employers with respect to applicants and employees who are not covered as disabled persons under the ADA. Clearly the privacy of personal medical information is important for applicants and employees whether or not they are covered by the ADA. It can be assumed that many persons with genetic predispositions for disease will not be covered by the ADA because these persons have no current manifestation of disease that would limit major life activities. ⁿ²⁰⁶ When a person has a genetic predisposition for disease, such as a genetic marker for increased risk of breast cancer, the genetic information is not usually related to the person's current ability to perform a job, making adverse **employment** action on this basis very unfair.

In contrast to the ADA's lack of express protection for applicants and employees against genetic discrimination, federal employees are protected from discrimination on the basis of genetic information under Executive Order 13145 (Executive Order). ⁿ²⁰⁷ The Executive Order was issued by [*133] former President Clinton in 2000. ⁿ²⁰⁸ The EEOC enforces the Executive Order's protections. ⁿ²⁰⁹ The Executive Order defines "protected genetic information" (PGI) and broadly prohibits discrimination in federal **employment** against applicants and employees based on their PGI. ⁿ²¹⁰ Employees of private employers and other government employees who work for state and local governments are not protected by the Executive Order. ⁿ²¹¹

The EEOC issued interpretive guidance on the Executive Order's protections against discrimination on the basis of genetic information for federal employees. ⁿ²¹² This guidance provides insight on the potential for federal regulation of genetic discrimination and genetic privacy in private-sector workplaces. ⁿ²¹³ The guidance also addresses the relationship between genetic discrimination and disabilities covered by the ADA, [*134] including ADA coverage for persons with actual disabilities, those with a record of a disability, and those regarded as having a disability. ⁿ²¹⁴ For example, under the EEOC's guidance, a person with a misspelled or altered gene associated with a severe disease or disorder has an actual disability and is covered under the ADA. ⁿ²¹⁵ The EEOC's guidance says that an alteration or a misspelling in a gene is an ADA-covered "impairment" because it causes cellular and molecular changes leading to disturbances in cell function, although not all physical or mental impairments will be covered by the ADA. ⁿ²¹⁶ Because ADA-covered impairments are limited to those that substantially limit a major life activity, genetic impairments that are covered by the ADA are likely limited to those that relate to serious or fatal diseases.

Additionally, persons who are carriers of misspelled or altered genes that cause serious or fatal diseases that may be passed to offspring are likely to be covered by the ADA. ⁿ²¹⁷

Health care providers, including self-insured employers who provide medical insurance benefits directly for their employees, also have privacy obligations under the medical confidentiality rules of HIPAA. ⁿ²¹⁸ HIPAA [*135] gives employees covered by an employer's self-insured plan a right to access and review their personal information for accuracy, similar to rights reserved for employees to access and review their personal information under the EU Privacy Directive and national implementing **laws**. ⁿ²¹⁹

One significant drawback of HIPAA in terms of protecting the privacy of applicants' and employees' genetic information is that it does not apply to employers acting as employers, even if the employers are also sponsors of self-insured health insurance plans that cover employees. ⁿ²²⁰ If genetic information or other PHI makes its way from a HIPAA-regulated health insurance provider to an employer, it is not a violation of HIPAA for the employer to use that information in a way that violates expectations of privacy or constitutes **employment** discrimination. ⁿ²²¹ Because HIPAA does not apply in the **employment** context, applicants and employees must turn to the ADA, state tort **laws**, or other federal or state **laws** for any remedies for privacy violations or discrimination related to genetic information. ⁿ²²²

[*136] In sum, the ADA is the only federal statute that provides privacy protection in the workplace for medical information of private-sector employees. It is best described as a civil rights statute designed to prevent **employment** discrimination against persons with disabilities. However, the medical confidentiality protections found in the ADA are very similar to the privacy protections for employees' personal data found in the EU and national implementing **laws**. One significant difference is that employees' remedies for a violation of the ADA are superior to those provided in the EU. Under the ADA employees have a private cause of action for damages for disability discrimination and may recover actual damages, compensatory damages (including damages for emotional distress), and punitive damages, subject to caps on compensatory and punitive damages. ⁿ²²³

*C. State **Laws** Regulating Genetic Privacy and Nondiscrimination in the Workplace*

At least thirty-two states have statutes that prohibit genetic discrimination in **employment**. ⁿ²²⁴ A significant number of states prohibit requesting genetic information or a genetic test (eighteen states), requiring genetic information or a genetic test (twenty-five states), performing a genetic test (sixteen states), or obtaining genetic information including a genetic test result (ten states). ⁿ²²⁵ However, only twelve states with statutes prohibiting genetic discrimination have specific penalties for genetic discrimination in **employment**. ⁿ²²⁶

Other authors have previously analyzed state genetic discrimination **laws** that restrict the use of genetic information and testing by employers. ⁿ²²⁷ [*137] There are at least four possible approaches in state statutes to combat genetic discrimination in **employment** that are possible models for federal legislation:

(1) a **law** that bans genetic testing and discrimination in **employment** with no exceptions; (2) a **law** that generally prohibits genetic discrimination unless it is based on a genetic characteristic that is a BFOQ [bona fide occupational qualification] (e.g., Massachusetts); (3) a **law** that generally prohibits employers from using genetic information unless the workplace presents a known, irreducible risk of serious, untreatable disease or condition to a subpopulation of workers whose unusual susceptibility can be determined through genetic testing (i.e., Michael Yesley's suggestion); or (4) a **law** that generally prohibits employers from using genetic information unless the employer uses the information to protect the health or safety of employees (e.g., Nebraska). ⁿ²²⁸

One important criticism of the use of state **laws** to regulate the use of genetic information in the workplace is that the nature of information about employees sharing is interstate, so it is unlikely that state **laws** could ever adequately protect genetic privacy. ⁿ²²⁹ "As medical records are increasingly stored and transferred electronically and then made available in centralized data banks, state **laws** that attempt to address privacy directly may be largely irrelevant." ⁿ²³⁰ Another criticism is that while over half of the states have state legislation prohibiting **employment** discrimination, fewer than half of these states restrict genetic testing or otherwise protect employees' privacy with respect to genetic information, leaving employees in at least half of the states with little privacy protection. ⁿ²³¹ A third criticism of existing state **laws** is that state regulation is inconsistent in such important matters as: (1) definitions of genetic information, genetic testing, and genetic discrimination; (2) required procedures to protect privacy of genetic information; and (3) providing adequate penalties for violations to deter violations by employers. ⁿ²³²

[*138] *D. Proposed Federal Legislation Regulating the Collection and Use of Genetic Information in the Workplace*

The proposed Genetic Information Nondiscrimination Act of 2005 is the culmination of over eight years of collaborative effort to enact federal-legislation regulating the use of genetic information by employers and health insurers. ⁿ²³³ In 2005 the Senate passed the Genetic Information Nondiscrimination Act of 2005 (S. 306), and a bill by the same name is pending in the House (H.R. 1227). ⁿ²³⁴ The bill pending in the House is virtually identical to the bill passed by the Senate, so this section will analyze the potential impact of S. 306 on workplace privacy and nondiscrimination by employers. Title I of S. 306 also regulates genetic privacy and nondiscrimination by group health insurance plans, ⁿ²³⁵ but the impact on the insurance industry is not covered by this discussion. ⁿ²³⁶

In S. 306, the Senate made findings about examples of genetic discrimination in the workforce, including pre-**employment** screening that was the basis of a court decision in favor of employees in *Norman-Bloodsaw v. Lawrence Berkeley Laboratory*. ⁿ²³⁷ The Senate also made findings with respect to state genetic nondiscrimination **laws**, noting that these **laws** vary widely with respect to their approach, application, and level of protection. ⁿ²³⁸ The purpose of the Genetic Information Nondiscrimination Act of [*139] 2005 is to provide uniform national protection to allow individuals to take advantage of advances in genetic testing and therapies without fear of workplace (and health insurance) discrimination. ⁿ²³⁹

Under S. 306, covered employers are defined consistently with Title VII of the Civil Rights Act of 1964 and the ADA, so only employers with fifteen or more employees are covered. ⁿ²⁴⁰ Both applicants and employees of covered employers are protected from genetic discrimination by S. 306. ⁿ²⁴¹

Using a three-prong definition of genetic information, S. 306 covers "information about -- (i) an individual's genetic tests; (ii) the genetic tests of family members of the individual; or (iii) the occurrence of disease or disorder in family members of the individual." ⁿ²⁴² However, the definition excludes information about the sex or age of an individual. ⁿ²⁴³ S. 306 also covers the use of genetic monitoring, ⁿ²⁴⁴ genetic services, ⁿ²⁴⁵ and genetic tests in the workplace. ⁿ²⁴⁶

Genetic discrimination prohibited by S. 306 includes all negative **employment** actions based on an applicant's or an employee's genetic [*140] information or based on a request for genetic services by the applicant or employee or a member of his or her family. Prohibited genetic discrimination includes: refusal to hire, discharge, and job assignments that deprive employees of **employment** opportunities. ⁿ²⁴⁷

S. 306 restricts collection of genetic information. It prohibits requesting, requiring, or purchasing genetic information about applicants, employees, and their family members, unless the collection of genetic information is permitted by one of five statutory exceptions.ⁿ²⁴⁸ These narrow exceptions permit collection of employees' genetic information when the request is:

- (1) Inadvertent, as part of a request for employee or family medical history;
- (2) Pursuant to genetic services offered by an employer through a bona fide wellness program;
- (3) Covered by certification provisions of the federal Family and Medical Leave Act;
- (4) Purchased by the employer as documents that are commercially and publicly available (including newspapers, magazines, periodicals and books, *but not including medical databases or court records*) that include family medical history; or
- (5) For information to be used for genetic monitoring of biological effects of toxic substances in the workplace.ⁿ²⁴⁹

Permitted genetic workplace monitoring for toxic substances is subject to tight restrictions to protect employees from discrimination and protect their privacy.ⁿ²⁵⁰ Employers may only conduct genetic monitoring if the employer has provided prior written notice of the genetic monitoring to employees, the employer has obtained written authorization from employees for monitoring, or the monitoring is required by state or federal **law**.ⁿ²⁵¹ If genetic monitoring is conducted, employees must be informed of [*141] their individual monitoring results.ⁿ²⁵² Employers must conduct genetic monitoring in compliance with any federal genetic monitoring regulations, including regulations to be promulgated by the Secretary of Labor under this act and state regulations promulgated under federal occupational safety and health **laws**.ⁿ²⁵³ Only licensed health care professionals or board certified genetic counselors may receive the results of genetic monitoring in a form that reveals individual employees' information.ⁿ²⁵⁴ This means that employers generally receive results of genetic monitoring only in the aggregate and are not entitled to receive genetic information that reveals the identity of specific employees.ⁿ²⁵⁵ Further S. 306 prohibits employers from using genetic information obtained through genetic monitoring in violation of the nondiscrimination rules.ⁿ²⁵⁶

The privacy protections created by S. 306 include nondisclosure rules for employers.ⁿ²⁵⁷ Generally applicants' and employees' genetic information will be treated as a confidential medical record.ⁿ²⁵⁸ Consistent with the medical confidentiality rules established under the ADA, genetic information must be maintained on separate forms and in separate medical files and treated as confidential medical records.ⁿ²⁵⁹ However, the permitted disclosures for genetic information differ from those permitted by the ADA. Significantly, unlike the medical confidentiality rules under the ADA, supervisors are not permitted access to genetic information about employees.ⁿ²⁶⁰ Employers may not disclose genetic information to anyone except the employee, an occupational or other health researcher, or in response to a court order.ⁿ²⁶¹

[*142] Under S. 306 employees have a private right of action to sue their employers for violations of the genetic privacy and discrimination protections under this act.ⁿ²⁶² This means that applicants and employees whose rights are violated under the Genetic Nondiscrimination Act of 2005 will be able to sue for damages consistent with those available for sex, race, and other forms of discrimination.ⁿ²⁶³ These damages include actual damages in the form of lost wages and benefits, compensatory and punitive damages (including emotional distress damages, but subject to caps that limit these damages to no more than \$ 300,000 based on the size of the employer), and costs and attorney's fees to

prevailing parties. ⁿ²⁶⁴ S. 306 only prohibits intentional discrimination and does not cover disparate impact claims. ⁿ²⁶⁵ Consistent with the **employment** discrimination regulation under the ADA, the EEOC is responsible for enforcing Title II of the Genetic Nondiscrimination Act of 2005. ⁿ²⁶⁶

In sum, the genetic privacy and nondiscrimination protections provided for applicants and employees under S. 306 are well balanced. ⁿ²⁶⁷ S. 306 will protect applicants and employees from unfair nondiscrimination and its medical confidentiality rules provide basic privacy protections with respect to personally identifiable genetic information. It also preserves employer prerogatives to use genetic information for legitimate purposes to manage workplaces without unduly restricting employers' ability to use technologies made possible by genetic research, including advances in genetic testing that will help employers monitor and protect the health and safety of employees from toxic workplace exposures.

[*143] **V. THE EU APPROACH TO GENETIC PRIVACY AND NONDISCRIMINATION IN THE WORKPLACE**

Europeans are clear in their respect for equality and privacy. Both rights receive recognition and protection at the supranational level under regional human rights treaty **law** and EU legislation. Both rights are honored in public and private workplaces in the EU Member States. Interestingly, the EU was intended to be an economic union, with human rights and other social policy concerns considered only as an afterthought. ⁿ²⁶⁸

However, now through a series of decisions by the [European Court of Justice], Directives of the Council, treaty revisions, the adoption of the Charter of Fundamental Rights of the European Union, and the ongoing discussion of a new Constitution for the EU, the entrenchment of human rights in the fabric of EU **law** has become a reality. ⁿ²⁶⁹

The issue of genetic privacy and nondiscrimination in the workplace is for the first time forcing a convergence of at least the two fundamental rights of equality and privacy for the Member States and evoking widely variable responses.

Like the United States, the EU is currently taking up the issue of protecting genetic data from unlawful and unethical uses by those with access to that data. ⁿ²⁷⁰ Protection of individual genetic data originates in the EU Convention. ⁿ²⁷¹ Article 11 of the EU Convention prohibits any form of discrimination against an individual on the basis of genetic data. ⁿ²⁷² Article 12 targets predictive genetic testing and states:

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health [*144] purposes or for scientific research linked to health purposes, and subject to appropriate genetic counseling. ⁿ²⁷³

Violation of the EU Convention results in a right of the individual affected to sue for money damages and/or financial sanctions against the infringer. ⁿ²⁷⁴

EU authorities consider the protection of genetic data to be a pre-requisite for ensuring the principle of equality in Member States. ⁿ²⁷⁵ European treaty **law** enshrines this right and guarantees it to citizens throughout the EU. ⁿ²⁷⁶ The nondiscrimination provisions found in European treaties are particularly relevant in the context of advances in bio-medicine and the accessibility of citizens' genetic data. For example, Article 21 of the Charter of Fundamental Rights of the European Union states: "any discrimination based on . . . genetic features . . . shall be prohibited." ⁿ²⁷⁷ According to the explanatory text, this nondiscrimination provision draws on Article 11 of the EU Convention which prohibits any form of discrimination on the basis of genetic heritage. ⁿ²⁷⁸

The right to nondiscrimination on the basis of genetic data is guaranteed to all EU citizens without distinction as to the context in which that right might be challenged. Thus, employees in the EU are protected, at least at the supranational EU treaty level, from **employment** discrimination tied to their genetic features. However, preventing genetic discrimination requires first and foremost protecting the privacy of workers' genetic information. ⁿ²⁷⁹ If the information is unavailable, discrimination on the basis of genetic traits is impossible because, unlike race or gender, genetic traits [*145] cannot be detected by casual observation. ⁿ²⁸⁰ This is no less true in the EU where there are perceived limitations in the ability of existing antidiscrimination **law** to realistically combat discrimination on the basis of genetic data. For example, the EU adopted Council Directive 2000/78/EC of November 27, 2000 establishing a general framework for equal treatment in **employment** and occupation (Equal Treatment in **Employment** Directive). ⁿ²⁸¹ The stated purpose of the Equal Treatment in **Employment** Directive is to create minimum requirements for Member States in combating discrimination on the basis of religion or belief, disability, age, or sexual orientation in both the public and private sphere. ⁿ²⁸² Genetic information may provide a detailed picture of a person's physical disposition and health condition. ⁿ²⁸³ Such data may also describe specific forms of a wide range of physical characteristics, including those that may reveal a real or potential future disability in the employee or job applicant. ⁿ²⁸⁴ Although the Equal Treatment in **Employment** Directive prohibits direct and indirect discrimination on the basis of disability, it does allow for the possibility that it may be legitimate to require employees to have specific physical characteristics in certain occupations and that an employer's definition of those physical requirements could constitute a genuine occupational requirement. ⁿ²⁸⁵ An employee's failure to exhibit a particular set of physical characteristics through genetic testing may actually legitimize **employment** discrimination on that basis.

Existing disability discrimination **law** in the Member States may not be adequate to protect employees against all discrimination tied to genetic [*146] data. For example, the United Kingdom's Disability Discrimination Act of 1995, which applies to all employers with fifteen or more employees, provides employees with adverse genetic test results some protection from discrimination by employers, assuming they are currently employed and the tests were completed for a reason related to their disability. ⁿ²⁸⁶ However, the definition of "disability" under the Act does not include people who have a susceptibility to a *future* disability. ⁿ²⁸⁷ Employers can thus avoid the Act by refusing to hire "presymptomatic" individuals who might be entitled to protection under the Act at a later date. ⁿ²⁸⁸ Additionally there is no "regarded as disabled" provision in the United Kingdom Act as exists in U.S. disability **law**, which may protect U.S. employees with genetic abnormalities against **employment** discrimination. ⁿ²⁸⁹

Some Member States have initiated a review of genetic discrimination in the workplace and have even legislated restrictions on genetic testing or use of genetic data in the **employment** context. However, absent specific legislation prohibiting **employment** discrimination on the basis of genetic data, the EU is not far removed from the United States in its current state of reliance on the ADA for employee protection from genetic discrimination. In the interim, the limitations inherent in existing **employment** discrimination **laws** in the EU highlight the need to rely on other existing **law**, namely privacy **law**, to prevent or restrict genetic testing and restrict further access to any personal data that may be revealed as a result of that testing. This is where the convergence of the rights to equality and privacy peaks.

The right of privacy is of fundamental significance and guaranteed in European treaty **law**, namely the European Convention for the Protection of Human Rights and Fundamental Freedoms and the more recent Charter of Fundamental Rights of the European Union, both of which guarantee [*147] for Europeans the right to privacy. ⁿ²⁹⁰ Workplace privacy

derives first from the general right to privacy guaranteed all EU citizens in these treaties. It also derives significantly from data protection **law** which regulates the processing of personal data by statute. The EU adopted Directive 95/46/EC (Privacy Directive) of the European Parliament and of the Council on October 24, 1995, on the protection of individuals with regard to the processing of personal data and on the free movement of such data. Personal data is defined in the Privacy Directive as information relating to an identified or identifiable natural person, "who can be identified, directly or indirectly, in particular reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity."ⁿ²⁹¹

The Privacy Directive applies only to the processing of personal data, not the ownership of it. Processing is broadly defined as "any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as *collection, recording, organization, storage, adaptation or alteration, retrieval, . . . use, . . . dissemination, etc.*"ⁿ²⁹² Individuals ("data subjects") are assured certain rights with respect to their personal data while "data controllers" are required to follow rules and restrictions with respect to their data processing operations, including disclosing to data subjects the identity of any data controller and the purposes for which personal data is being collected.ⁿ²⁹³

The spirit of the Privacy Directive is encapsulated in its core principles of data privacy protection. These principles define the rights of individual data subjects and the responsibilities of data controllers in the context of processing personal data, regardless of the context (consumer, **employment**, etc.). Pursuant to the Privacy Directive personal data may be collected only for specified, explicit, and legitimate purposes and may not be processed in any way that is inconsistent with those purposes. This is commonly referred to as the "finality principle."ⁿ²⁹⁴ The purpose of the [*148] processing itself must be legitimate ("legitimacy principle")ⁿ²⁹⁵ and the data subject must be fully informed on the details of the processing, including who has access to the data, how it is stored, and how the subject can review it ("transparency principle").ⁿ²⁹⁶ The "proportionality principle" requires that personal data be adequate, relevant, and not excessive in relation to the purposes for which it is collected and further processed.ⁿ²⁹⁷ In other words, data controllers may only access data to the extent necessary and through means that are the least intrusive given the underlying purpose for the processing. In the context of genetic testing by employers, this may allow for testing to ensure the health and safety of current employees and for satisfying compliance with Member State occupational safety **laws**, but would not justify the use of that same data for **employment** determination decisions.

As a direct and mandatory result of the Privacy Directive, today there are national data protection **laws** in the Member States of the EU that are administered by local data protection authorities.ⁿ²⁹⁸ The Privacy Directive has caused dynamic amendment and modification of Member States' data protection **laws** to be consistent with the core principles enshrined and made applicable to all processing of personal data in the EU.ⁿ²⁹⁹

The Privacy Directive's application to the **employment** relationship is well established in EU interpretative documents, Member State legislation, court decisions, and scholarly writings.ⁿ³⁰⁰ Its application to the processing of genetic data in the **employment** context was confirmed in 2004 by the EU authority on data protection, the Article 29 Data Protection Working Party, in its Working Document on Genetic Data (2004 Document on Genetic Data).ⁿ³⁰¹ According to the Working Party, genetic data by [*149] definition is personal data. In fact, because genetic data may be associated with data concerning health and data concerning ethnic origin, genetic data is entitled to heightened protection as "sensitive data" under the Privacy Directive.ⁿ³⁰² Sensitive data may only be processed in "exceptional" circumstances. In the case of genetic data that means that the processing must be

necessary for the purposes of preventative medicine, medical diagnosis, the provision of care or treatment, or the management of health care services. ⁿ³⁰³ Additionally genetic data may only be processed according to specific conditions, such as by a health professional subject to the obligation of medical secrecy or by another person subject to an equivalent obligation of secrecy. ⁿ³⁰⁴

The Working Party reminds Member States in the 2004 Document on Genetic Data that the core privacy principles of finality and proportionality are immediately invoked in the context of genetic data. "Considering the complexity and the sensitivity of [sic] genetic information, there is a great risk of misuse and/or reuse for various purposes by the data controller or third parties." ⁿ³⁰⁵ It would, for example, be a violation of the finality principle to re-use genetic information already extracted as a blood sample in the course of a pre-**employment** medical exam for additional analysis to test for sickle cell trait. Under the proportionality principle an employer seeking information through that same blood test for confirmation of general good health could not test further for specific genetic traits which might be used to predict the longevity of that good health condition.

The Working Party has concluded that the processing of genetic data in the **employment** relationship should be prohibited in principle and only authorized under very exceptional circumstances, taking into account the ban against such processing already in force in several Member States. Unfortunately, the Working Party does not provide examples of "exceptional [*150] circumstances" except to state that they should be provided for by **law**. This leads to an examination of existing Member State legislation on the subject and any clarification of the circumstances under which an employer can process genetic data. ⁿ³⁰⁶

What follows is a discussion of the Privacy Directive's impact on the regulation of employer processing of employee genetic data. Included is an overview of specific Member States' regulation of genetic testing and use of genetic data in the **employment** context.

A. Application of the Privacy Directive to Processing Genetic Information in the Workplace

The Privacy Directive fully applies to the workplace and thus regulates employees' data protection needs, albeit in light of Member States' social policy and labor **law**. ⁿ³⁰⁷ The Privacy Directive has a direct and immediate effect on the human resource operations of employers. ⁿ³⁰⁸ There are many examples of **employment** records involving the processing of personal data covered by the Privacy Directive, including: application forms and work references; payroll and tax information; social benefits information; sickness records; annual leave records; unpaid leave/special leave records; annual appraisal/assessment records; records relating to promoting, transfer, training, and disciplinary matters; and records related to accidents at work. ⁿ³⁰⁹ Often the processing of such data includes very sensitive data by the data controller, here the employer or an agent of the employer contracted for that purpose.

[*151] In the EU, employees' privacy rights are balanced against the interest of employers in validating the processing of employees' personal data. The EU recognizes that employers have a legitimate interest in processing such personal data for purposes that are connected to the normal development of the **employment** relationship and business operations. ⁿ³¹⁰ The issue is not whether data processing at the workplace is per se unlawful, but rather "which are the reasons that may justify the collection and further processing of personal data of any given worker." ⁿ³¹¹

Pursuant to the Privacy Directive, employees are granted a number of rights with respect to the collection of their personal information by employers, including the right to be generally

informed about information collection practices, the right to access and correct personal information held by employers, and in some cases, the right to actually withhold consent to the collection and processing of data by employers. ⁿ³¹² If an employee believes that his or her rights are being violated, he or she may appeal to the supervisory authority, called the Data Protection Authority (DPA) in the appropriate Member State for relief, or seek damages in a judicial proceeding. ⁿ³¹³ Employers are liable for monetary compensation to employees whose rights under the Privacy Directive are violated, as well as liable for any additional sanctions under relevant national data protection **law**. ⁿ³¹⁴

The Privacy Directive is the point of origin in the EU for determining the extent of privacy protection for employees with respect to the processing of their personal information, including genetic data which is considered "sensitive data." Some genetic data is initially acquired by genetic [*152] testing, which is itself a type of medical testing that may either involve genetic screening or genetic monitoring. ⁿ³¹⁵ Both types produce personal data that is highly sensitive in nature, thus falling into the regulation rubric of the Privacy Directive.

Article 8 of the Privacy Directive addresses the processing of special categories of data. It states: "Member States *shall prohibit* the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership and the processing of data concerning health or sex life." ⁿ³¹⁶ While genetic data is not specifically named, the Working Party has interpreted "data concerning health" and even "data revealing racial or ethnic origin" to include genetic data. ⁿ³¹⁷

B. Exceptions to the Ban on Processing Employees' Sensitive Genetic Data

Article 8 establishes an immediate ban on the ability of employers in the EU to access and account for employees' sensitive medical information, which arguably includes by extension genetic information. However, there are some notable exceptions to the prohibition on processing sensitive data which could be relevant to the processing of genetic data within the **employment** relationship, namely, employee consent and employer-provided preventative medicine or health care services. ⁿ³¹⁸ It may be the case that these exceptions to the Article 8 ban are what the Working Party was contemplating in its definition of "exceptional circumstances" in the 2004 Document on Genetic Data.

[*153] The prohibition on processing sensitive data does not apply where the data subject, here the employee, has given his or her "explicit consent" to the processing of the data. ⁿ³¹⁹ Member States are permitted to disregard this exception in their implementing legislation, or instead they may require that the worker's representative body (e.g., trade union or works council) also consent. ⁿ³²⁰ It is noteworthy that the concept of consent as a way to legitimize **employment** practices under EU **law** is not quite as straightforward as the concept of consent under U.S. **law**, particularly in the workplace context where there is economic pressure on the employee and withholding consent can have immediate negative job consequences. ⁿ³²¹ The Working Party has taken the view that where as a necessary and unavoidable consequence of the **employment** relationship an employer has to process personal data, it is misleading if it seeks to legitimize this processing through consent. "Reliance on consent should be confined to cases where the worker has a genuine free choice and is subsequently able to withdraw the consent without detriment." ⁿ³²² In other words, "if it is not possible for the worker to refuse it is not consent." ⁿ³²³

For example, the Belgian **Law** on Data Protection provides that processing of sensitive data is allowed if the data subject has given written consent, so long as that consent may be withdrawn by the data subject at any time. ⁿ³²⁴ Interestingly, the Belgian Data Protection **Law** also stipulates that a Royal Decree may be issued to indicate cases in which consent

will not legitimize the processing of sensitive data. Article 27 of the Royal Decree of February 13, 2001 in fact requires that if the processing of personal data involves sensitive or *health-related* data, the data subject's consent will not make the processing lawful *if* the data controller is the current or

[*154] potential employer of the data subject. In other words, under Belgian **law** the employee's consent will not lift the ban on the employer's processing of sensitive data. Employers in Belgium will not be able to legitimize the processing of employee genetic data on the basis of employee consent.

Compare this to Portugal's approach under its data protection **law** where sensitive data is defined to actually include genetic data. The Portuguese Data Protection Act provides that processing of sensitive data is permitted where authorized in advance by its DPA when the processing is essential for exercising the legal or statutory rights of the controller (here employer), or when the data subject (employee) has given his or her explicit consent, in both cases with guarantees of nondiscrimination. ⁿ³²⁵ The **law** does not provide specifics related to the parameters of these guarantees or their enforceability.

With respect to sensitive data that is health-related data, which appears to include genetic data, there is an exception that may permit processing of this type of genetic data in an **employment** context. Article 8(3) allows for the processing of data where: required for the purposes of preventative medicine, medical diagnosis, the provision of care or treatment or the management of health-care services, *and* where those data are processed by a health professional subject under national **law** or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy. ⁿ³²⁶

In the EU there are labor **law** traditions in certain Member States that incorporate a concept of occupational medicine as a form of preventative medicine in the **employment** context. In some of these jurisdictions, employee consent will still be required where there are company health justifications for the processing of health-related (i.e., genetic data) information. ⁿ³²⁷

Again Portugal provides a good example of the relationship between the use of health services under existing **employment law** and data protection **law**. Portuguese **employment law** mandates the creation of occupational health services for all workers to protect them against sickness, disease, and injury. These services are responsible for employees' medical examinations and also for the examination of job applicants. Specifically they are responsible [*155] for such tasks as admission examinations for general health fitness, health assessment of workers before assignment to a position that may involve health risks, and health assessment on the resumption of work after an extended leave of absence for health reasons to determine possible occupational causes and the need for rehabilitation or reassignment. ⁿ³²⁸

The Portuguese Data Protection Act complements Portuguese **employment law** by allowing for validation of employee medical examinations with the explicit consent of employees; however, the Act in this instance again requires the approval of the DPA. The Portuguese Data Protection Act mirrors Article 8(3) of the Privacy Directive and allows for the processing of health, sexual, *and genetic* data if necessary for the purposes of preventative medicine, medical diagnosis, the provision of care or treatment, or the management of health-related services. ⁿ³²⁹ If the processing of the data is not for one of these purposes, an authorization from the DPA is required. The DPA will thereafter authorize the employer to complete the processing when the employee's consent is obtained or when the processing is essential for the legal or statutory rights of the employer. ⁿ³³⁰

In comparison, the French Bill of **Law** on Data Protection similarly authorizes occupational medicine as a category of permissible sensitive data processing so long as that processing is executed by a health professional obligated by a duty of confidentiality. The French bill also highlights genetic data and like the Portuguese Act mandates that prior approval to the processing of genetic data be given by the French DPA, unless "the processing is necessary for the purposes of preventative medicine, medical diagnosis or the administration of medical care or treatment." ⁿ³³¹ However, the French bill goes beyond the Portuguese Act by clarifying that employers are not entitled to specific medical or health information about employees. In general, employers are not permitted to collect medical data about employees and any purported **employment** decision based on medical data about employees collected by the employer is void and without any legal value. ⁿ³³² Employees must be healthy enough to take a position,

[*156] but that determination is made by an independent medical professional who is under a duty of confidentiality and may not disclose to an employer any details about the health status of employees. The medical professional, who is a civil servant, may simply state whether or not an employee is fit for a position. An employer who disregards the opinion of the medical professional may be liable under French criminal **law**.

In addition to national legislation implementing the Privacy Directive, some Member States have considered the issue of genetic testing and processing in **employment laws** specifically devoted to genetics. ⁿ³³³ For example, in Austria genetic testing is governed by the Gene Technology Act (**Law** BGB 510/1994), which forbids employers from obtaining, requesting, taking, or otherwise using genetic data of employees or job applicants. ⁿ³³⁴ Other Member States have not legislated the specific issue of genetic discrimination, but incorporate reference to genetic data in data protection **laws** regulating the processing of sensitive data, as evidenced in the French bill discussed above. ⁿ³³⁵ Finland provides an interesting example of a country that has supplemented its data protection **law** to address the processing of sensitive data in the specific sector of "working life." ⁿ³³⁶ Its Act on Data Protection in Working Life prohibits employers from requiring a job applicant or an employee from taking part in genetic testing. In fact, employers are prevented from knowing about any genetic testing that employees or applicants have undergone even if there is explicit consent to sharing that information. ⁿ³³⁷ Enforcement is accomplished through a fine imposed on the employer for violating the Act on Data Protection in Working Life. ⁿ³³⁸ Still other Member States make no reference at all to genetic data in their national data protection **laws**. ⁿ³³⁹ In that case, employers [*157] must rely on the interpretation of the Working Party in its 2004 Document on Genetic Data and any available DPA interpretations for guidance regarding the legality of genetic testing of employees. ⁿ³⁴⁰

Although there is an obvious lack of uniformity in the EU with respect to the processing of genetic data in the workplace, some general parameters for employers in the EU contemplating the need or desirability of genetic testing is offered based on the analysis of existing **laws**. In the absence of specific legislation on genetic information and testing, employers should begin their consideration with Article 8 of the Privacy Directive which imposes a ban on the processing of employees' genetic data unless there is a relevant exception. The relevant exceptions have been examined in detail above. In the **employment** context these exceptions are: (1) employee consent, (2) employer legal need, and (3) occupational medicine. Employers should recognize that if they seek to legitimize the processing of employee genetic data on the basis of exceptions (1) and (2), they will likely need the prior approval of the DPA in the relevant Member State. Of course, some Member States such as Belgium do not permit the employee consent exception, but others may permit this, with DPA approval and appropriate guarantees against employee discrimination. If an employer seeks to legitimize the processing of genetic data on the

basis of exception (3), there will likely be no need for prior approval of the DPA so long as the processing is conducted for the purposes of preventative medicine, medical diagnosis, or the administration of medical [*158] care or treatment. However, in that event the person conducting the testing should be an independent medical professional who in most Member States will be obligated by a duty of confidentiality to protect employees' privacy with respect to their genetic data. The employer will not be privy to the details of the genetic test results, and its knowledge may be limited to general employees' fitness, as compared to any predictive screening of future employees' health.

VI. JURISDICTIONAL COMPARISON REVEALS INSIGHTS THAT INSPIRE ADVOCACY OF A MODIFIED U.S. APPROACH

This section of the article compares the U.S. and EU approaches to regulation of genetic privacy and nondiscrimination in order to analyze the strengths and weaknesses of S. 306. ⁿ³⁴¹ A comparison of the federal statutes that protect the privacy and nondiscrimination of U.S. and EU employees in the context of genetic information and genetic testing is provided in Exhibit A. ⁿ³⁴² Existing regulations including the ADA and the EU's Privacy Directive are analyzed in this exhibit, as well as proposed federal legislation in the United States and the recommendations of the Article 29 Working Party for new EU legislation.

In theory employees in Europe currently have broader personal data protections than employees in the United States because the Privacy Directive sets broad rules to govern the processing of most personal data in most business contexts. However, existing exceptions to the Privacy Directive's restrictions on processing of employees' personal data leave room for employers to process some genetic information lawfully. ⁿ³⁴³ Further, the Privacy Directive does not include any prohibition on workplace discrimination by employers based on employees' genetic information and does not provide any remedies for this type of **employment** discrimination. If the Article 29 Working Party's recommendations for legislation on genetic [*159] data are followed, new EU legislation will be adopted that will expressly cover genetic information processed by employers. Further, this new legislation will ban all use of genetic information by employers except in exceptional circumstances. ⁿ³⁴⁴ The new legislation will also provide minimum protections against workplace discrimination based on one's genetic profile that would ostensibly be uniform throughout the EU.

One of the key differences between existing U.S. and EU **law** is that regulators in the two jurisdictions take fundamentally different policy approaches: one takes a data protection approach, while the other takes a civil rights approach. The United States treats genetic information in the workplace as a civil rights issue. ⁿ³⁴⁵ This approach leads to legislation that is predominately designed to address misuses of genetic information as workplace discrimination, and acquiring and using employees' genetic information in **employment** decisions is one form of discrimination. In contrast, the EU has consistently followed a data protection approach, recognizing that individuals have a right to control their personal data and requiring employers to justify any processing of that data based on legitimate business needs. ⁿ³⁴⁶ Neither regulatory approach directly creates workplace privacy rights and both fail to comprehensively analyze genetic information in the workplace from a theoretical privacy perspective. ⁿ³⁴⁷ The EU's data protection approach more closely approximates a privacy approach by recognizing that employees have legitimate interests in controlling their personal data that should take precedence except where legitimate business needs of the employer justify employer control and use of the data. On the other hand, the ADA and proposed legislation such as S. 306 primarily create civil rights to be free from unfair **employment** [*160] actions. The concepts of medical confidentiality found in the ADA and S. 306, however, do create **employment** rights that resemble privacy rights, although these rights are encompassed in broader civil rights to be free from genetic discrimination.

A significant weakness of the EU's data protection approach is that it does not directly address unfair uses of genetic information by EU employers. If an employer is able to justify its collection and use of EU employees' personal data within the current framework of data protection, unfair uses of genetic information will not be regulated by the Privacy Directive. One might argue that the EU's data protection approach better protects employees' privacy because employers who cannot obtain personal data about employees including genetic information also cannot inappropriately use the data. However, as discussed previously, available exceptions under the Privacy Directive may permit abuses by employers in this regard.

A significant weakness of the U.S. approach is that the ADA does not adequately protect employees from discriminatory use of their genetic information because only disabled employees are currently protected by the scope of this **law**.ⁿ³⁴⁸ S. 306 will remedy this problem by covering all employees working for employers with fifteen or more employees whether or not they are "disabled."ⁿ³⁴⁹ Another weakness of the ADA is that it is unclear that there is any remedy for employees when an employer fails to maintain the confidentiality of employees' medical records, thus letting the employee's genetic information "out," but the employer's breach of the ADA's confidentiality rules is not accompanied by adverse **employment** action. For example, assume an employee's HIV-positive status is disclosed by an employer and that, as a result of the disclosure, the employee's coworkers learn that the employee is HIV-positive. Such disclosures by employers may be deliberate or inadvertent. In either case the employee may experience emotional distress and incur economic and noneconomic injuries from the disclosure of her private medical information. But when there has been no harassment or other adverse **employment** action, arguably there has been no **employment** discrimination, and there is no remedy under the ADA.

[*161] If S. 306 is adopted and an employer fails to keep an employee's genetic information confidential, will there be a remedy to compensate the employee for having his or her genetic information revealed to others? No doubt the employee will experience emotional distress and other injuries in this situation. But if no adverse **employment** action is taken against the employee whose genetic information is disclosed in violation of S. 306, arguably there is no remedy. Ultimately, S. 306 is a discrimination **law** and does not provide adequate remedies for invasions of privacy that are not accompanied by adverse **employment** actions. The employee in such circumstances will have to depend on privacy tort **laws** for a remedy. Fortunately, as discussed in Part IV above, there is some authority for finding a remedy in tort in these circumstances.ⁿ³⁵⁰ The medical confidentiality standards established by S. 306 should enhance the likelihood of recovery for privacy torts in cases involving improper disclosure of employees' genetic information because it will be easier for employees to prove they had a reasonable expectation of privacy in their genetic information and that the actions of employers who failed to maintain confidentiality were unreasonable.

The medical confidentiality rules of S. 306 are a significant improvement over the current void of privacy rights for employees with respect to genetic information in the workplace. But S. 306 does not go far enough to protect employees' privacy and amendments to S. 306 are needed to address these defects and provide more comprehensive privacy protection for employees. One significant improvement would be to amend S. 306 to specify that an employer's failure to follow the medical confidentiality rules is a specific act of **employment** discrimination. This small change would make the remedies in S. 306 for **employment** discrimination applicable to employers' breaches of confidentiality. Alternatively, S. 306 should be revised to include a specific remedy for employees to compensate them for their employers' failure to keep genetic information confidential. This alternative would provide

flexibility for Congress to create different remedies for deliberate and inadvertent breaches of confidentiality that would be available in the absence of other adverse **employment** action. This flexibility could be used to address circumstances where a breach of confidentiality, absent other **employment** discrimination, was not viewed as justification for the standard discrimination remedies.

[*162] Other areas of improvement in S. 306 can be derived from examining S. 306 in light of the EU's Privacy Directive. ⁿ³⁵¹ First, the concept of sensitive data in the Privacy Directive is a helpful starting point to analyze the desired scope of the privacy protections needed in S. 306. Sensitive data under the Privacy Directive includes personally identifiable data related to health, sex, age, and ethnic origin. In contrast S. 306 expressly excludes coverage of genetic information related to sex and age, although other federal civil rights statutes already prohibit discrimination based on race, national origin, sex, and age. ⁿ³⁵² Existing civil rights statutes in the United States do not, however, provide any privacy protection for employees' data related to race, national origin, sex, and age, and will not protect the privacy of genetic information that reveals these sensitive forms of personal information. Broader privacy protection to include these forms of sensitive personal data should be part of S. 306.

Second, additional improvements for S. 306 are revealed by examining S. 306 in light of the seven fundamental privacy principles found in the Privacy Directive: necessity, finality, transparency, legitimacy, proportionality, data accuracy, and security. ⁿ³⁵³ The necessity principle requires that any collection of genetic information be absolutely necessary for the employer's purpose. ⁿ³⁵⁴ On its face, S. 306 exceeds the strict necessity standard for collection of genetic data that is found in the Privacy Directive because S. 306 absolutely prohibits requesting, requiring, or purchasing genetic information unless one of several narrow exceptions applies. ⁿ³⁵⁵ However, the exceptions in S. 306 sometimes swallow the rule and eliminate the need for an employer to demonstrate strict necessity. For example, under the employee authorization exception, employers are not required to show the request for genetic information is necessary before obtaining employee consent. ⁿ³⁵⁶

[*163] The finality principle requires data to be collected only for a specific, explicit, and legitimate purpose and not be processed in any way incompatible with that purpose. ⁿ³⁵⁷ Again, S. 306 absolutely prohibits collection of genetic information by employers unless one of several narrow exceptions applies and thus goes beyond finality under its general rules. However, when an exception applies, S. 306 does not require finality as to processing of genetic data, although it does prohibit some processing of genetic data if the processing would constitute unlawful genetic discrimination. S. 306 should be amended to provide finality.

The transparency principle requires employers to be open and clear about their activities. ⁿ³⁵⁸ S. 306 promotes transparency, for example, by requiring employers to inform employees of their individual monitoring results, but not to the extent required by the Privacy Directive. When genetic monitoring is permitted under S. 306, S. 306 does not always require employees to be informed in advance of the testing. For example, employees are not entitled to advance notice of genetic monitoring when they have given prior consent or monitoring is required by state or federal **law**. ⁿ³⁵⁹ Also, there is no general right of employees to review their medical files as provided under the Privacy Directive. ⁿ³⁶⁰ S. 306 should be amended to require advance notice of all genetic monitoring and give employees the right to review their medical files.

The legitimacy principle means processing of workers' personal data itself must be legitimate as that term is defined in the Privacy Directive. ⁿ³⁶¹ Legitimate processing includes

processing that is: necessary for compliance with a legal obligation of the employer, necessary for performance of a contract between the employer and worker, or covered by unambiguous consent of the worker. ⁿ³⁶² If it is not possible for the employee to refuse to [*164] consent, the consent is not valid in the EU. ⁿ³⁶³ In contrast, S. 306 requires employee consent to be prior, knowing, voluntary, and written, but does not address situations where consent may not be truly voluntary because the employee is required to consent to obtain or keep a job. S. 306 should be amended to give employees the right to refuse consent to genetic testing without risking their jobs.

The proportionality principle mandates that personal data must be adequate, relevant, and not excessive in relation to the purposes for collection and/or further processing. ⁿ³⁶⁴ Under this principle, any collection of genetic data by an employer must be tailored to the type and degree of risk the employer faces. S. 306 does not require employers to identify the risk that is being minimized or addressed by genetic testing as would be required to justify the degree of intrusiveness of the particular genetic test by the principle of proportionality. When an employer is permitted to collect genetic data under S. 306, there is no additional requirement that the collection be proportional to the employer's need for the data. S. 306 should be amended to limit employers' collection of genetic data to achieve proportionality.

The principle of data accuracy mandates that all records must be accurate, up to date, and retained for no longer than necessary given the legitimate purposes of the employer. ⁿ³⁶⁵ There is no express requirement of data accuracy in S. 306. Data accuracy could be improved for **employment** records containing genetic data by giving employees a statutory right to review their medical records for accuracy. S. 306 should be amended to permit the EEOC to adopt administrative regulations to require employers to keep their records up to date and to require employers to set data retention policies consistent with legitimate business purposes.

Finally, the security principle requires employers to implement appropriate technical measures at the workplace to guarantee that personal data of employees is kept secure. ⁿ³⁶⁶ Beyond the medical confidentiality requirements of S. 306, there are no specific security provisions required for genetic data in the workplace. Security of genetic data could be [*165] improved if S. 306 was amended to authorize the EEOC to adopt administrative regulations for the security of genetic data.

While the privacy and nondiscrimination provisions of S. 306 could be substantially improved, the recommendations here do not mirror the EU's Article 29 Working Party's recommendation that "all processing of genetic data in the field of **employment** should be prohibited in principle." ⁿ³⁶⁷ This position is both unworkable and undesirable for workplaces in the United States because it precludes even beneficial uses of genetic data and genetic monitoring in the workplace. As discussed earlier in this article, there are beneficial uses of genetic data and genetic monitoring in the workplace that include prevention and detection of workplace exposures to toxic substances and voluntary wellness programs. The approach of S. 306 is much more balanced and is appropriate for the United States. Instead of banning all processing of genetic data and genetic testing in the workplace, S. 306 sets tight parameters on these activities that seek to protect employee privacy and prevent unfair discrimination. Yet S. 306 also enables employers to monitor workplaces for toxic substances and protect employees from the biological effects of toxic substances in the workplace.

In sum, comparison of S. 306 to the EU's Privacy Directive, including the concept of sensitive data and its seven data protection principles, reveals some significant potential improvements that should be made to S. 306 to improve workplace privacy in genetic

information. However, the current bill provides privacy and nondiscrimination rights for employees that greatly outweigh its disadvantages. Even without further amendments, S. 306 would establish baseline privacy and nondiscrimination rights for applicants and employees related to their genetic information and protect them from unfair genetic testing in the workplace.

VII. CONCLUSION

Previous studies of the policy and legal issues related to advances in genetic science and the workplace have focused on the desirability of regulating employers' access, use, and disclosure of genetic information about [*169] employees. ⁿ³⁶⁸ These studies advocate a privacy approach that seeks to protect employees' rights to autonomy and control of personal information. Other studies have focused on the need to regulate unfair uses of genetic information and genetic testing by employers. ⁿ³⁶⁹ Essentially, both approaches are correct because they address important policy issues related to the workplace. As a matter of public policy, both privacy and non-discrimination are essential policy goals for legislation on the topic of workplace privacy and nondiscrimination and effective legislation needs to address both goals simultaneously.

Exhibit A

Comparison of U.S. and EU Genetic Privacy and Nondiscrimination Protections for Private-Sector Workplaces

	U.S.	U.S.
	ADA	Proposed Federal Legislation (S. 306)
Categories of Personal Data Protected	Medical information & disability-related information.	Genetic information, which includes genetic test information, but not if related to sex or age.
Covered Employers	Only employers with 15 or more employees.	Employers with 15 or more employees.
Covered Applicants & Employees	Only "disabled" applicants & employees are protected from discrimination. Includes those with actual disabilities, those regarded as disabled, and those with records of a disability.	All applicants and employees of covered employers.
Expressly Covers Genetic Information in the Workplace	No, but EEOC administrative guidance states the ADA covers genetic information, including genetic test results.	Yes.
Restricts Collection and	Yes, establishes time-	Yes, it is unlawful

Processing of Protected Data that includes Genetic Information	frames related to permissible collection of medical information, including medical exams and disability-related inquiries.	to request, require, or purchase genetic information unless written authorization by employee or an exception applies.
Restricts Disclosure of Protected Data	Yes, medical information is required to be kept in separate files with restricted access and disclosure.	Yes, requires treatment of genetic information as a confidential medical record and severely restricts disclosure.
Prohibits Employment Discrimination Based on Genetic Information	Yes, provided the genetic information is "disability related information."	Yes.
Prohibits Genetic Testing	No, but prohibits applicant medical tests before extending a job offer and requires tests of employees to be job-related.	Yes, but several exceptions including genetic monitoring of toxic workplace exposures.
Applicants & Employees Have a Private Right of Action	Yes, but must file an administrative complaint and receive a right to sue letter from the EEOC before filing a lawsuit.	Yes, but must file an administrative complaint and receive a right to sue letter from the EEOC before filing a lawsuit.
Monetary and Other Civil Remedies Available to Applicants & Employees for Violations	Yes, monetary damages with caps for compensatory and punitive damages.	Yes, remedies are the same as ADA.
Criminal Penalties for Violations	No.	No.

EU
Privacy Directive

EU
Article 29 Working Party's
Recommendations for
Legislation on Genetic

Categories of Personal Data Protected	Personal data relating to an identified or identifiable natural person. Sensitive data, including data related to health, race, ethnic origin, and sex life.	Data Adopts definitions from various international instruments that generally define as any type of data related to hereditary characteristics of an individual or concerning a pattern of inheritance within a related group.
Covered Employers	All.	All.
Covered Applicants & Employees	Yes.	Yes.
Expressly Covers Genetic Information in the Workplace	No.	Yes, would expressly cover genetic information processed by employers.
Restricts Collection and Processing of Protected Data that includes Genetic Information	Yes, there is a general ban on the processing of sensitive data. Exceptions are made for consent, employer's legal obligations, and preventative medicine.	Yes, would continue ban and in employment context permit only in exceptional circumstances. In no case would mass genetic screening be permissible.
Restricts Disclosure of Protected Data	Yes, all processing, including disclosure, must be consistent with core privacy principles of transparency, security, legitimacy, etc.	Yes, all processing, including disclosure, must be consistent with the core privacy principles of the Privacy Directive, particularly proportionality and finality.
Prohibits Employment Discrimination Based on Genetic Information	No.	Yes, would explicitly prohibit and require guarantees of nondiscrimination.
Prohibits Genetic Testing	No.	No, but would prohibit mass genetic screening. Testing would need to be

		consistent with privacy principles of finality and proportionality.
Applicants & Employees Have a Private Right of Action	Depends on national implementing legislation.	Will depend on national implementing legislation.
Monetary and Other Civil Remedies Available to Applicants & Employees for Violations	Depends on national implementing legislation.	Will depend on national implementing legislation.
Criminal Penalties for Violations	Depends on national implementing legislation.	Will depend on national implementing legislation.

Although S. 306 may best be characterized as civil rights legislation, enactment of this bill would significantly regulate privacy and discrimination related to genetic information and testing in the workplace. S. 306 would directly address gaps perceived in existing legislation (e.g., ADA and HIPAA) that make these federal statutes unwieldy as tools to prevent and redress misuse of genetic information in the workplace. If S. 306 becomes **law** in the United States, applicants and employees will have substantial privacy and nondiscrimination protections related to their genetic information that are not dependent on status as disabled persons. ⁿ³⁷⁰ The privacy and nondiscrimination protections found in S. 306 will protect all applicants and employees except those that work for small employers with fewer than fifteen employees. ⁿ³⁷¹ Importantly, the nondiscrimination protections in S. 306 are tough. Generally S. 306 will prohibit employers from acquiring employees' genetic data and from using this information in **employment** decisions in ways that are adverse to employees. It will also specifically regulate **employment** practices involving genetic testing. ⁿ³⁷²

Essentially S. 306 complements existing federal **laws** that define protected classifications for those treated adversely due to gender, race, national origin, religion, disability, or age. It creates new civil rights by establishing a new federally protected classification for employees to be used to protect employees from discrimination based on their genetic [*170] information. The result of creating a new federally protected classification for genetic information is that many more applicants and employees will be protected by the new federal **law** prohibiting genetic discrimination than would be protected under the ADA. Further, the new protections under S. 306 include substantial legal remedies in the form of damages and attorney's fees that are recoverable for those whose rights are violated. ⁿ³⁷³

If S. 306 becomes **law**, U.S. workers will also have significant privacy rights with respect to their genetic information that they currently do not have. As Exhibit A details, these privacy rights are framed in terms of requirements for medical confidentiality that provide privacy protections by restricting employers from collecting genetic information in the first place, and from disclosing genetic information in other cases. ⁿ³⁷⁴ These privacy rights make it unlawful for an employer to request, require, or purchase genetic information unless it has written authorization from an employee or one of several other narrow exceptions applies. S. 306 will also require covered employers to treat genetic information as a confidential medical record, thus protecting employees' privacy. These confidentiality rules are much tougher than the current standards for medical confidentiality under the ADA because they

prohibit employers from disclosing employees' genetic information to supervisors or other managers who might use that information negatively in **employment** decisions.

Yet, we argue that the privacy protections to be afforded by S. 306 do not go far enough. A remedy for breach of confidentiality should be included in S. 306 that would compensate employees if their private genetic information is improperly disclosed by their employers. Further, S. 306 should be examined in light of the seven important data protection principles found in the EU's Privacy Directive, and, as outlined in this article, amendments to the bill should be proposed consistent with these principles. There is adequate time to address these important privacy matters while the proposed legislation is being considered in the House, or later in a joint conference committee.

Even if the suggested improvements to S. 306 that are outlined in this article are not achieved, proposed federal legislation regulating genetic information in the workplace should be adopted. S. 306 would provide minimum privacy and nondiscrimination standards related to genetic [*171] information in the workplace. Once these minimum nondiscrimination and privacy standards are in place, there will be additional opportunities to enhance these workplace protections through statutory amendments or regulatory interpretations.

This article raises potential troubling misuses of employee genetic data; however, advances in genetic science have actually increased the potential for genetic information to be used for "good." Workplace **laws** should not discourage the further advance of genetic science that could protect employees from workplace hazards that are presently unknown and unaddressed. While U.S. regulators can and should learn much from the comprehensive privacy protections enjoyed by Europeans, the proposed genetic privacy and nondiscrimination legislation in the United States builds on unique strengths found in the U.S. system of workplace regulation and offers pragmatic solutions that should not unduly interfere with employers' prerogatives to manage the ever-evolving twenty-first century workplace.

Legal Topics:

For related research and practice materials, see the following legal topics:
Workers' Compensation & SSDI
Compensability
Injuries
Cumulative Injuries
Healthcare
Law
Business Administration & Organization
Patient Confidentiality
Health Insurance
Portability & Accountability Act
Labor & Employment Law
Employee Privacy
Medical & Related Examinations

FOOTNOTES:

[n1](#) The hypothetical situation described in this paragraph is based on the circumstances that led to litigation by employees of a government-operated research facility who were required to submit to preplacement medical examinations that included undisclosed genetic testing for sickle cell trait, as well as testing for other sensitive medical conditions like pregnancy and syphilis. See [Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1270-73 \(9th Cir. 1998\)](#) (reversing the district court's dismissal of this case on summary judgment because material factual issues on the employees' state and federal constitutional privacy claims existed that merited trial; affirming dismissal of the employees' federal disability claims).

[n2](#) "Sickle cell anemia, or sickle cell disease, is a chronic inherited anemia in which a large proportion or the majority of red blood cells tend to sickle." MERRIAM WEBSTER'S COLLEGIATE DICTIONARY 1089 (10th ed. 1996). "Sickle-cell trait is an inherited blood condition in which some red blood cells tend to sickle but usually not enough to produce anemia, which occurs primarily in individuals of African, Mediterranean, or southwest Asian ancestry, and which results from heterozygosity for a semidominant gene." *Id.* As explained by the court in *Norman-Bloodsaw*:

The sickle cell gene is only semi-dominant: if the carrier of the gene is heterozygous (meaning that the gene is paired with a non-sickle cell gene), some of his or her red blood cells may sickle, but usually not to a sufficient degree to result in actual sickle cell anemia.

123 [5 F.3d at 1265.](#)

[n3](#) See *supra* note 2 for a discussion of sickle cell trait and sickle cell anemia.

[n4](#) This hypothetical is based on the circumstances involving unauthorized genetic testing by a railroad employer of employees who had filed work-related disability claims for carpal tunnel syndrome, leading to a lawsuit filed by the employees' union representatives and litigation filed by the Equal **Employment** Opportunity Commission (EEOC). See EEOC v. Burlington N. Santa Fe Ry., Civ. No. 01-4013 MWB (N.D. Iowa April 18, 2001) (granting an order related to a preliminary settlement agreement); see also Patricia A. Roche, *The Genetic Revolution at Work: Legislative Efforts to Protect Employees*, 28 AM. J.L. & MFD. 271, 272 (2002) (discussing the action brought by the EEOC against Burlington North Santa Fe Railway after the agency received complaints from employees that the company had been secretly testing their DNA).

[n5](#) Carpal tunnel syndrome is a condition caused by compression of a nerve where it passes through the wrist into the hand and is characterized by weakness, pain, and disturbances of sensation in the hand. MERRIAM WEBSTER'S COLLEGIATE DICTIONARY 174 (10th ed. 1996).

[n6](#) Roche, *supra* note 4, at 276.

[n7](#) See Frank Hendrickx, *Protection of Workers' Personal Data in the European Union: General Issues and Sensitive Data*, in PROTECTION OF WORKERS' PERSONAL DATA IN THE EUROPEAN UNION: TWO STUDIES 15 (2002), available at http://europa.eu.int/comm/employment_social/labour_law/docs/dataprotection_hendrickx_combinedstudies_en.pdf (reporting that most Member States have **laws**, or are in the process of preparing new **laws**, that transpose the EU Privacy Directive into national legislation); see also Data Privacy Directive, Council Directive 95/46, 1995 O.J. (L 281) 31 [hereinafter Privacy Directive].

[n8](#) The recent enlargement of the EU admitted ten new countries to membership in the EU, bringing EU membership to 25 countries. See Europa, *1st May 2004 -- The EU's 5th Enlargement*, at <http://www.eudelindia.org/en/enlargement/enlargement.htm> (last visited Sept. 3, 2005) (reporting that Cyprus, The Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia, and Slovenia had been admitted to the EU). Initially, the EU consisted of just six countries: Belgium, Germany, France, Italy, Luxembourg, and the Netherlands. Europa, *The European Union at a Glance*, at http://europa.eu.int/abc/index_en.htm (last visited Sept. 3, 2005). Denmark, Ireland, and the United Kingdom joined in 1973, Greece in 1981, Spain and Portugal in 1986, and Austria, Finland, and Sweden in 1995. *Id.* Several other European countries are expected to

join the EU in the next few years. *Id.*

[n9](#) See Privacy Directive, *supra* note 7; see also Hendrickx, *supra* note 7, at 15.

[n10](#) See Hendrickx, *supra* note 7, at 15.

[n11](#) See Article 29 Data Protection Working Party, Working Document on Genetic Data (March 17, 2004) available at http://europa.eu.int/comm/justice_home/fsj/privacy/docs/wpdocs/2004/wp91_en.pdf [hereinafter WPD 2004].

[n12](#) See *id.*; see also Hendrickx, *supra* note 7, at 82-85.

[n13](#) See, e.g., *Genetic Nondiscrimination in the Workforce: Hearing on H.R. 1910 Before the House Comm. on Educ. and the Workforce*, 108th Cong. (2004) (testimony of Kathy Hudson, Ph.D., Director, Genetics and Public Policy Center [hereinafter Hudson's Congressional Testimony] reporting on the progress in genome science to facilitate diagnosis of genetic conditions and guide treatment decisions, provide prognostic information that can help tell the course of a disease, or provide probabilistic predictive information about the future risk of disease); Richard S. Fedder, *To Know or Not to Know*, 21 J. LEGAL MED. 557, 564 (2000) (commenting on the trend by health care providers to use centralized electronic records to store information about patients' medical care); Pauline T. Kim, *Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace*, 96 Nw. U. L. REV. 1497, 1511-12 (2002) (commenting that advances in computer technology have contributed to advances in genetic science and the prevalence of genetic information by permitting simpler, less expensive techniques for simultaneously detecting hundreds, or even thousands, of genetic mutations).

[n14](#) See WPD 2004, *supra* note 11.

[n15](#) See Lasprogata et al., *Regulation of Electronic Employee Monitoring: Identifying Fundamental Principles of Employee Privacy Through A Comparative Study of Data Privacy Legislation in the European Union, United States and Canada*, 2004 STAN. TECH. L. REV. 4 (2004) (providing a comparison of workplace privacy laws in the EU, United States, and Canada).

[n16](#) *Id.* PP 66-69, 108-110; Exec. Order No. 13,145, 65 Fed. Reg. 6,877 (Feb. 10, 2000) (prohibiting discrimination in federal employment based on genetic information).

[n17](#) Genetic Information Nondiscrimination Act of 2005, H.R. 1227, 109th Cong. § 1 (2005) [hereinafter H.R. 1227].

[n18](#) Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2005) [hereinafter ADA].

[n19](#) Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191, 110 Stat. 1936 [hereinafter HIPAA] (codified as amended in scattered sections of 29 U.S.C. and 42 U.S.C.).

[n20](#) Genetic Information Nondiscrimination Act of 2005, S. 306, 109th Cong. § 1 (2005) [hereinafter S. 306]; H.R. 1227, *supra* note 17.

[n21](#) S. 306, *supra* note 20; *Bill Tracking Report S. 306* (2005), LEXIS 109 Bill Tracking S.

306 (introduced 2/7/05; passed, as amended, 2/17/05).

[n22](#) H.R. 1227, *supra* note 17, *Bill Tracking Report HR 1227* (2005), LEXIS 109 Bill Tracking H.R. 1227 (introduced: 3/10/05; last action 3/10/05).

[n23](#) 151 Cong. Rec. S 1,050 (daily ed. Feb. 7, 2005) (statement of Sen. Snowe) [hereinafter 2005 Statement of Senator Snowe Introducing S. 306].

[n24](#) Genetic Information Nondiscrimination Act of 2003, S. 1053, 108th Cong. (2003); *Bill Tracking Report S 1053* (2003), LEXIS 108 Bill Tracking S. 1053 (introduced 5/13/03; passed by the Senate 10/14/03). The House Committee on Education and the Workforce held hearings on the proposed legislation in July 2004. *Genetic Nondiscrimination in the Workforce: Hearing on H.R. 1910 Before the House Comm. on Educ. and the Workforce*, 108th Cong. (2004).

[n25](#) 149 CONG. REC. S12493 (daily ed. Oct. 14, 2003) (passing the Genetic Information Non-discrimination Act of 2003 after debate and a unanimous vote); *see also* Sheryl Gay Stolberg, *Senate Sends to House a Bill on Safeguarding Genetic Privacy*, N.Y. TIMES, Oct. 15, 2003, at A1.

[n26](#) *See id.* at A1.

[n27](#) WPD 2004, *supra* note 11, at 10.

[n28](#) The scope of this article does not include examination of all situations where an employer's knowledge of an employee's genetic information would be relevant or irrelevant to **employment** decisions. This is a subject that will need to be explored further due to the need for medical experts to be involved in the examination of these issues. In this article we provide a few examples of situations where an employer's knowledge of an employee's genetic information appears relevant, from our perspective based on legal expertise rather than medical expertise, to **employment** decisions. For example, it is known that persons with alpha-1-antitrypsin deficiency are predisposed to emphysema and other lung diseases. *See* James K. Stoller, *Clinical Manifestations and Natural History of Alpha-1-antitrypsin Deficiency*, UPTODATE at <http://www.uptodate.com> (last visited Jan. 4, 2005) (listing articles reporting studies that support the relationship between occupational exposures to dust and smoke and the risk of developing emphysema for persons with this genetic deficiency). So, for example, knowledge of this predisposition is at least arguably relevant to placing an employee in a job that involves coal dust exposure, asbestos exposure, or even exposure to cigarette smoke. *Id.* On the other hand, whether an employee has sickle cell trait is probably not relevant to job placement, because such persons do not have the active disease of sickle cell anemia and will not develop the disease. Rather they only possess the potential to pass along the trait to their biological children, who may develop the disease if they have inherited the sickle cell trait from both parents. *See supra* note 2 for a discussion of sickle cell trait and sickle cell anemia.

[n29](#) Hudson's Congressional Testimony, *supra* note 13.

[n30](#) The U.S. Department of Energy and the National Institute of Health jointly coordinated the **international** research effort known as the Human Genome Project. *See* Ashley M. Ellis, Comment, *Genetic Justice: Discrimination By Employers and Insurance Companies Based on Predictive Genetic Information*, [34 TEX. TECH. L. REV. 1071, 1074 \(2003\)](#). Scientists involved in the project were engaged in mapping the complete sequence of the DNA in the human genome, which essentially created a map of the entire genetic structure

of the human species. *Id.* "The map is then used to develop new ways to treat, cure and prevent diseases that afflict humankind." *Id.* See also Jennifer M. Jendusa, Comment, *Pandora's Box Exposed: Untangling the Web of the Double Helix in Light of Insurance and Managed Care*, 49 DEPAUL. L. REV. 161, 165-70 (1999) (providing an introduction to genes, basic genetics, and the Human Genome Project); Department of Energy, Biological and Environmental Research Program, *Human Genome Research*, at http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml (last visited Jan. 15, 1995).

[n31](#) See, e.g., Hendrickx, *supra* note 7 (providing two studies of the protection of workers' personal data in the EU: the first study examines general issues and sensitive data including genetic information and the second study examines surveillance and monitoring at work); WPD 2004, *supra* note 11 (providing a general outline of the technical progress in the field of genetic research that has given rise to new data protection questions that relate to genetic tests and the processing of genetic data). Numerous studies in the United States also explore these issues. See, e.g., Jennifer Krumm, *Why Congress Must Ban Genetic Testing in the Workplace*, 23 J. LEGAL MED. 491, 491 (2002) (providing an overview of the advances of genetic science, referencing studies of the prevalence of genetic testing in the workplace, and reporting instances of workplace discrimination on the basis of genetics). See also Hudson's Congressional Testimony, *supra* note 13, at 4 (reporting the results of a recent survey of 4834 Americans by the Genetics and Public Policy Center). The survey showed that Americans generally approve of genetic testing procedures to benefit health but are concerned about who will have access to genetic test results. *Id.* Ninety-two percent of respondents in the survey said employers do not have the right to know about genetic test results showing that individuals have an increased risk for disease. *Id.* See also Paul Steven Miller, *Genetic Discrimination in the Workplace*, 26 J.L. MED. & ETHICS 189 (1998) (reporting that eighty-five percent of respondents felt that there should be prohibitions against employers or insurers having access to an individual's genetic information); Glendora Hughes, *Genetically Incorrect: Genetic Privacy and Protection in the Work-place*, MD. B.J., Jan. -- Feb. 2002, at 34, 36-37 (summarizing surveys that document workers' fear of inappropriate use of genetic information by employers).

[n32](#) Hughes, *supra* note 31, at 36-37.

[n33](#) Aart C. Hendriks, *Genetics, Data Protection and Non-Discrimination: Some Reflections From An **International** Human Rights **Law** Perspective*, 20 MED. & L. 37, 39 (2001) (providing an examination of the implications of genetics on the rights to privacy, notably data protection and the right not to be discriminated against). Genetic information differs from other medical information in some significant ways, including the use of genetics as a historical basis for discrimination against certain ethnic and racial groups that society has justified through genetic characteristics (such as sterilization policies and insurance and **employment** discrimination against carriers of the sickle cell trait) and the fact that genetic information is not just information about one individual but also includes information about blood relatives. See Ellis, *supra* note 30, at 1081-91. Genetic information also differs from medical information because medical and social studies show that learning about one's genetic information can have a negative impact on self-concept, personal relationships, and views on pregnancy and can lead to stigmatization and discrimination by others. *Id.*

[n34](#) Michael S. Yesley, *Protecting Genetic Difference*, 13 BERKELEY TECH. L.J. 653, 659-62 (1998) (providing a survey of current federal and state legislation related to genetic privacy and discrimination in **employment** and insurance, as well as **laws** that protect genetic privacy; commenting on the difficulty of defining "genetic data" or "genetic information").

[n35](#) See [id. at 661](#).

[n36](#) Practically every clinical test can be considered a test for gene products because most clinical tests detect abnormal concentrations of biochemical entities and thus may provide information about the genes that code for those entities as well as the functioning of various organs. *Id.*

[n37](#) A narrow definition of genetic information that is limited to the results of direct tests of applicants or employees for gene alterations does not prevent employers from discriminating on the basis of indirect tests or family medical history, which may reveal information about an individual's genetic predisposition for disease. *Id.*

[n38](#) See *infra* notes 245-47 and accompanying text.

[n39](#) MASS. GEN. **LAWS** .ch 151B, § 1(23) (2004). The Massachusetts statute defines "genetic test" to cover "any tests of human DNA, RNA, mitochondrial DNA, chromosomes or proteins for the purpose of identifying genes or genetic abnormalities, or the presence or absence of inherited or acquired characteristics in genetic material." *Id.*

[n40](#) Erik T. Juengst, *FACE Facts: Why Human Genetics Will Always Provoke Bioethics*, [32 J.L. MED. & ETHICS 267, 270-72 \(2004\)](#) (arguing that there is something special about human genetics from a moral point of view that justifies its continued prominence on the future agenda of bioethics).

[n41](#) See [id. at 272-73](#) (reporting that genetic research may be used to identify individuals in terms of larger human populations, such as ethnic groups and/or racial groups).

[n42](#) Gender is basic information that can be revealed by genetic testing. For example, genetic testing could reveal that an employee observed to be living as a female is genetically a male, perhaps leading to discovery of whether the employee had had a sex change operation. Interview with Destiny J. Brown, Third-Year Medical Student, Oregon Health Sciences University (Jan. 3, 2005).

[n43](#) A PUBLIC CONSULTATION ON OVERSIGHT OF GENETIC TESTS, SEC'Y'S ADVISORY COMM. ON GENETIC TESTING, NAT'L INST. OF HEALTH (Dec. 1, 1999-Jan. 31, 2000), available at http://www4.od.nih.gov/oba/sacgt/reports/Public_Consultation_document.htm. For an example of a statutory definition of genetic testing, see MASS. GEN. **LAWS**, *supra* note 39.

[n44](#) Jared A. Feldman & Richard J. Katz, *Genetic Testing & Discrimination in **Employment**: Recommending a Uniform Statutory Approach*, [19 HOFSTRA LAB. & EMP. L.J. 389, 393 \(2002\)](#).

[n45](#) 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, 554 \(1997\)](#); see also Jendusa, *supra* note 30, at 171.

[n46](#) Hendrickx, *supra* note 7, at 62; see also ELEC. PRIVACY INFO. CT., PRIVACY & HUMAN RIGHTS: AN **INTERNATIONAL** SURVEY OF PRIVACY **LAWS** AND DEVELOPMENTS 104 (2003) [hereinafter EPIC PRIVACY REPORT] (citing Leroy Hood & Lee Rowen, *Genes, Genomes, and Society*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 27 (Mark A. Rothstein ed., 1997)).

[n47](#) EPIC PRIVACY REPORT, *supra* note 46, at 105 (citing Leena Peltonen & Victor A. McKusick, *Genomics and Medicine: Dissecting Human Disease in the Postgenomic Era*, SCIENCE, Feb. 16, 2001, at 1224, available at <http://0-www.sciencemag.org.uncclc.coast.uncwil.edu:80/cgi/content/full/291/5507/1224>).

[n48](#) *Id.*

[n49](#) See Deyerle, *supra* note 45, at 554; see also Jendusa, *supra* note 30, at 171.

[n50](#) See Deyerle, *supra* note 45, at 554; see also Jendusa, *supra* note 30, at 171.

[n51](#) See Deyerle, *supra* note 45, at 554.

[n52](#) See *supra* notes 53-55 for a discussion of and references to alpha-1-antitrypsin deficiency.

[n53](#) See *id.* Even when a genetic trait may be relevant to some job placement decisions, the information may be used improperly and unfairly against employees in other contexts. See Ellis, *supra* note 30, at 1082-83 (discussing Congressional testimony of actual reported cases of genetic discrimination in the workplace). For example, Terri Sergeant of North Carolina was fired by her employer when she was diagnosed with alpha-1-antitrypsin deficiency. *Id.* At the time she was fired, Terri had been working for the employer for seven years, had excellent performance reviews, had received a recent salary increase for outstanding work, and had not yet manifested any physical symptoms of the disease. Terri's brother died of the disease when he was only thirty-seven years old. As a result of being fired, Terri was left without a job and had to pay her own medical expenses for enzyme replacement therapy to treat the disorder. *Id.*

[n54](#) See Deyerle, *supra* note 45, at 554.

[n55](#) See *id.*

[n56](#) See *id.* Because genetic monitoring may determine whether current exposure levels pose a health risk to employees resulting in enhanced use of safety protective equipment or changes to the workplace environment, monitoring may enhance employee and workplace health and safety. *Id.* This is a reason that genetic monitoring may be less objectionable from a discrimination standpoint. *Id.*

[n57](#) Interview with Destiny J. Brown, Third-Year Medical Student, Oregon Health Sciences University (Jan. 3, 2005).

[n58](#) *Id.*

[n59](#) Hudson's Congressional Testimony, *supra* note 13, at 3.

[n60](#) *Id.*

[n61](#) *Id.* Huntington's disease is a hereditary disease that usually develops in adult life and progresses to dementia. MERRIAM WEBSTER'S COLLEGIATE DICTIONARY 566 (10th ed. 1996).

[n62](#) Juengst argues that even "single gene disorder" diseases, like "recessive" cystic fibrosis and "dominant" Huntington's disease are multifactorial in the sense that they do not reliably

guarantee a particular clinical syndrome. Juengst, *supra* note 40, at 268. The complexity of genetic diseases often "mutes" the predictive power of most genetic information. *Id.* In fact, "DNA-based genetic risk assessments for most common health problems will not usually be able to predict the aspects of illness that will be most important to patients: the time of onset, the severity, the duration, or the treatability of their health problems." *Id.*

[n63](#) Fedder, *supra* note 13, at 560-61.

[n64](#) *Id.*

[n65](#) *Id.*; see also Allison Ito, *Privacy and Genetics: Protecting Genetic Test Results in Hawaii*, [25 U. HAW. L. REV. 449, 455-56 \(2003\)](#).

[n66](#) See Ito, *supra* note 65, at 456.

[n67](#) *Id.*

[n68](#) *Id.*; see also Fedder, *supra* note 13, at 563-65 (stating that "in most cases, it is not now cost-effective to randomly test otherwise healthy individuals for rare genetic defects, in part because the tests are still too expensive and in part because the number of false positives will overshadow the number of true positives").

[n69](#) See Hendriks, *supra* note 33, at 40-41.

[n70](#) See *id.*

[n71](#) See *id.* at 39.

[n72](#) Genetic tests are becoming less expensive and are more likely to be used more frequently by physicians for three reasons: In the first place, genetic testing is steadily moving from research labs to the clinical setting. Second, genetic disorders with a higher rate of occurrence in the population are being identified. Third, scientists are beginning to develop multifactor gene testing, which should ultimately be more cost-effective than individual gene testing. Consequently, rather than merely developing tests targeted at a specific gene coding for a particular genetic disease, it may soon be cheaper and more efficient for a physician to order one test that analyzes a number of genes at once. It is not hard to imagine, as costs decrease, that the time will come when genetic workups to probe common health "problem areas" will be ordered as part of routine physical examinations. See Fedder, *supra* note 13, at 563-64. There is little empirical evidence related to whether employers are more likely to require applicants and employees to undergo genetic tests. *But see, e.g.,* Deyerle, *supra* note 45, at 547-48 (summarizing the results of surveys of U.S. companies with regard to their use and/or plans to use genetic screening for **employment** decisions and reports of employers using genetic information to discriminate against applicants and employees). If genetic tests are used more frequently in the health care setting, genetic information about applicants and employees, including genetic test results, will be more available to employers, absent legal regulation to prevent this occurrence. As Fedder states: "Unless current **law** is changed, the results of genetic tests will be recorded on patients' medical records, which are widely accessible to insurers, employers and government agencies. The results will become even more accessible as medicine moves toward centralized electronic record keeping." Fedder, *supra* note 13, at 564. Added privacy restrictions on health care information that apply to health care providers have partially remedied this situation in the United States, although these regulations do not directly regulate employers' access and use of genetic information in the workplace. See discussion

of HIPAA *infra* notes 218-20 and accompanying text.

[n73](#) See Hendriks, *supra* note 33, at 41-42. Hendriks provides a list of **international** and regional human rights instruments that include privacy as a fundamental human right:

International:

- . The Universal Declaration of Human Rights (UDHA; Art. 12);
- . The **International** Covenant on Civil and Political Rights (ICCPR; Art. 17);
- . The Convention on the Rights of the Child (CRC; Art. 16).

Regional:

- . European Convention on Human Rights (ECHR; Art. 8).
- . American Convention on Human Rights (ACHR; Art. 11).
- . European Convention on Bioethics (Bioethics Convention; Art. 10).

Id. The European Convention on Bioethics is a relatively new treaty which seeks to complement the ECHR in an effort to protect the dignity and identity of all human beings and guarantees everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to application of biology and medicine. *Id.* See also H.D.C. Roscam Abbing, *The Convention on Human Rights and Bio-medicine: An Appraisal of the Council of Europe Convention*, 5 EUR. J. HEALTH L. 377 (1998).

[n74](#) See generally Hendriks, *supra* note 33, at 42; *supra* note 73.

[n75](#) See Hendriks, *supra* note 33, at 41-42.

[n76](#) *Id.*

[n77](#) *Id.*

[n78](#) See generally Privacy Directive, *supra* note 7.

[n79](#) See WPD 2004, *supra* note 11, at 10; Hendrickx, *supra* note 7, at 9 (expressly stating that the EU Privacy Directive covers the **employment** situation and therefore general principles of data protection must be applied to **employment**).

[n80](#) See [Lawrence v. Texas, 539 U.S. 558 \(2003\)](#) (protecting the right to engage in consensual sodomy in a private home); [Whalen v. Roe, 429 U.S. 589, 589 \(1977\)](#); [Roe v. Wade, 410 U.S. 113 \(1973\)](#) (protecting the right to abortion); [Loving v. Virginia, 388 U.S. 1, 12 \(1967\)](#) (protecting the right to marry).

[n81](#) See Jay P. Kesan, *Cyber-Working or Cyber-Shrinking?: A First Principles Examination of Electronic Privacy in the Workplace*, [54 FLA. L. REV. 289, 306 \(2002\)](#).

[n82](#) See *id.*; see also *supra* note 80.

[n83](#) See Kesan, *supra* note 81, at 306; William A. Wines & Michael P. Fronmueller, *American*

Workers Increase Efforts to Establish a Legal Right to Privacy as Civility Declines in U.S. Society: Some Observations on the Effort and its Social Context, [78 NEB. L. REV. 606 \(1999\)](#).

[n84](#) See Kesan, *supra* note 81, at 306-07.

[n85](#) See *id.* at 307.

[n86](#) Wines & Fronmueller, *supra* note 83, at 623.

[n87](#) See Kesan, *supra* note 81, at 307.

[n88](#) **Employment** at-will is a doctrine that allows employers to discharge an employee for almost any reason or for no reason, as long as the discharge is not contrary to a statute or a contract. Edwin Robert Cottone, Comment, *Employee Protection from Unjust Discharge: A Proposal for Judicial Reversal of the Terminable-At-Will Doctrine*, [42 SANTA CLARA L. REV. 1259, 1259 \(2002\)](#). Theoretically, the at-will doctrine is based on viewing the relationship between the employer and employee as a mutual relationship where either the employer or employee is free to terminate the relationship at any time. *Id.* Some notable exceptions to **employment** at-will mitigate the harshness of the at-will doctrine, such as federal or state discrimination **laws**. *Id.* at 1268-69. For example, it is unlawful under federal discrimination **laws** for an employer to treat employees differently with respect to terms and conditions of **employment** based on their sex, race, color, national origin, religion, age, or disability. *Id.* Generally speaking, many private-sector employees in the United States are at-will employees who give up any rights to privacy in the workplace by agreeing to work for the employer. Lawrence E. Rothstein, *Privacy or Dignity: Electronic Monitoring in the Workplace*, [19 N.Y.L. SCH. J. INT'L & COMP. L. 379, 382-83 \(2000\)](#); see also Stan Malos et al., *A Contingency Approach to the **Employment** Relationship: Form, Function and Effectiveness Implications*, 15 EMPLOYEE RESP. & RTS. J. 149 (2003) (comparing the U.S., Canadian, and New Zealand approaches to **employment** relationships). While at-will **employment** relationships are common in the United States, they are not the basis of **employment** relationships in much of the rest of the world. *Id.* at 156; cf. John T. Addison & Clive R. Belfield, *What Do We Know About the New European Works Councils? Some Preliminary Evidence from Britain*, 49 SCOT. J. POL. ECON. 418 (2002) (discussing the requirement of multinational employers to consult with worker representatives under the 1994 European Works Council Directive); Madeleine M. Plasencia, ***Employment-At-Will: The French Experience as a Basis for Reform***, 9 COME LAB. L.J. 294 (1988) (discussing French dismissal **law**); Tony Royle, *Worker Representation Under Threat? The McDonald's Corporation and the Effectiveness of Statutory Works Councils in Seven European Union Countries*, [22 COMP. LAB. L. & POL'Y J. 395 \(2001\)](#) (describing unionization rules in the EU). However, upon termination, even at-will employees in the United States may have remedies that far exceed those available to employees in countries that do not recognize at-will **employment**. See Malos et al., *supra*. Many of these monetary remedies relate to *how* employers handle terminations, not whether an employer can terminate an employee without advance notice. *Id.* Even at-will employees may recover monetary damages for the torts of defamation, invasion of privacy, intentional infliction of emotional distress, and constructive discharge, depending on how the employee was terminated. *Id.*

[n89](#) See Ito, *supra* note 65, at 457.

[n90](#) *Id.*

[n91](#) See WPD 2004, *supra* note 11, at 9.

[n92](#) *Id.*

[n93](#) *Id.*; see also Fedder, *supra* note 13, at 558 (discussing key elements in the debate over developing genetic privacy **law** including: informed consent, notice, mandatory disclosure, unauthorized disclosure, ownership of material that can be genetically tested, and control of the transmission and use of genetic data).

[n94](#) See Krumm, *supra* note 31, at 491; see also Deyerle, *supra* note 45, at 555 (defining genetic discrimination as "discrimination against an individual or against members of that individual family solely because of real or perceived differences from the normal' genome in the genetic constitution of that individual"). Only one **international** treaty, the Bromedecine Convention, refers to genetic heritage as a ground for nondiscrimination. See Hendriks, *supra* note 33, at 45. On a regional level, the EU Charter of Fundamental Rights (Art. 21) refers to "genetic traits." *Id.* Hendriks argues that differentiation, or the failure to differentiate, on the basis of genetic traits does not automatically lead to discrimination; but rather, it only constitutes discrimination in the absence of an objective and reasonable justification. *Id.* at 46.

[n95](#) See *id.*; Samantha French, *Genetic Testing in the Workplace: The Employer's Coin Toss*, 2002 DUKE L. & TECH. REV. 15, 15 (2002).

[n96](#) A genotype is all or part of the genetic constitution of an individual. MERRIAM WEBSTER'S COLLEGIATE DICTIONARY 486 (10th ed. 1996).

[n97](#) Deyerle, *supra* note 45, at 547-48.

[n98](#) *Id.* Deyerle states that employers have screened job applicants and employees in order to maintain productivity and to ensure workplace safety for years; such screening includes using medical screening and monitoring to exclude people from jobs, monitor employee health and safety, determine particular reasons for an employee's poor work performance, and study the effect of the workplace on employees. *Id.* Employer screening for such purposes has long been legally, ethically, and socially acceptable, and permitting inquiries into genetic conditions or predispositions in order to screen job applicants or to monitor employee health and safety seems a likely next step. *Id.* However, legal regulation of the use of genetic information by employers should be imposed to make sure that genetic screening does not mask "invidious discrimination against workers based on race, religion, ethnicity, or characteristics/disabilities that are irrelevant to job performance." *Id.* at 548.

[n99](#) See French, *supra* note 95, at 16-18 (commenting on potential liability for U.S. employers if they fail to use genetic information or genetic testing to its utmost potential, including possible tort liability for negligence for harm to third persons caused by employees that employers know, or should know, have dangerous propensities). For example, genetic tests may reveal that employees have genetic conditions that cause lapse of consciousness or incapacity that could result in harm to other persons in their care. *Id.* at 18.

[n100](#) See Krumm, *supra* note 31, at 492.

[n101](#) See Yesley, *supra* note 34, at 662. See also Kim, *supra* note 13, at 1508 (commenting that some researchers limit the term genetic discrimination to refer only to discrimination against asymptomatic individuals, while others do not).

[n102](#) Yesley, *supra* note 34, at 662. See, e.g., discussion of the ADA *infra* notes 167-99.

[n103](#) U.N. CHARTER. The U.N. Charter proclaims that "We the Peoples of the United Nations Determined . . . to reaffirm faith in fundamental human rights, in the dignity and worth of the human person. . . ." U.N. CHARTER pmb1.

[n104](#) *Universal Declaration of Human Rights*, G.A. Res. 217A (III), U.N. GAOR, 3d Sess., 67th plen. mtg., U.N. Doc. A/810 at 71 (1948) [hereinafter UDHR].

[n105](#) *Id.* art. 1.

[n106](#) *Id.* art. 2.

[n107](#) *Id.* art. 7.

[n108](#) **International** Covenant on Civil and Political Rights, *opened for signature* Dec. 16, 1966, 993 U.N.T.S. 171 (entered into force Mar. 23, 1976) [hereinafter ICCPR]. *See, e.g., id.* art. 2 (protecting the rights to equality and nondiscrimination):

Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

See also id. art. 26:

All persons are equal before the **law** and are entitled without any discrimination to the equal protection of the **law**. In this respect, the **law** shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

[n109](#) **International** Covenant on Economical, Social and Cultural Rights, *opened for signature* Dec. 16, 1966, 993 U.N.T.S. 3 (entered into force Jan. 3, 1976) [hereinafter ICESCR]. *See id.* art. 2(2): "2. The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." *See also id.* art. 7:

The States Parties to the present Covenant recognize the right of everyone to the enjoyment of just and favourable conditions of work which ensure, in particular:

(a) Remuneration which provides all workers, as a minimum, with:

(i) Fair wages and equal remuneration for work of equal value without distinction of any kind, in particular women being guaranteed conditions of work not inferior to those enjoyed by men, with equal pay for equal work;

(ii) A decent living for themselves and their families in accordance with the provisions of the present Covenant;

(b) Safe and healthy working conditions;

(c) Equal opportunity for everyone to be promoted in his **employment** to an appropriate higher level, subject to no considerations other than those of seniority and competence;

(d) Rest, leisure and reasonable limitation of working hours and periodic holidays with pay, as well as remuneration for public holidays.

[n110](#) See, e.g., ICCPR, *supra* note 108, pmb.: "Considering that, in accordance with the principles proclaimed in the Charter of the United Nations, recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." See *also id.* art. 17 (giving the right to privacy):" 1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. 2. Everyone has the right to the protection of the **law** against such interference or attacks." See *also id.* art. 26 (giving the right to be recognized as equal before the **law**):

All persons are equal before the **law** and are entitled without any discrimination to the equal protection of the **law**. In this respect, the **law** shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

[n111](#) UDHR, *supra* note 104. See *id.* art. 12: "No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the **law** against such interference or attacks"; see *also* ICCPR, *supra* note 108, art. 17: "1. No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. 2. Everyone has the right to the protection of the **law** against such interference or attacks."

[n112](#) *American Declaration of the Rights and Duties of Man*, O.A.S. Res. XXX, adopted by the Ninth **International** Conference of American States (1948), *reprinted in* Basic Documents Pertaining to Human Rights in the Inter-American System, OEA/Ser.L.V/II.82 doc.6 rev.I at 17 (1992). See *id.* art. 5: "Every person has the right to the protection of the **law** against abusive attacks upon his honor, his reputation, and his private and family life"; *id.* art. 9: "Every person has the right to the inviolability of his home"; *id.* art. 10: "Every person has the right to the inviolability and transmission of his correspondence." See *also* European Convention for the Protection of Human Rights and Fundamental Freedoms, *opened for signature* Nov. 4, 1950, art. 8, 213 U.N.T.S. 222 (entered into force Sept. 3, 1953):

1 Everyone has the right to respect for his private and family life, his home and his correspondence.

2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the **law** and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The American Convention on Human Rights, O.A.S. Treaty Series No. 36, 1144 U.N.T.S. 123 (entered into force July 18, 1978): Nov. 21, 1969, art. 11:

- 1 Everyone has the right to have his honor respected and his dignity recognized.
- 2 No one may be the object of arbitrary or abusive interference with his private life, his family, his home, or his correspondence, or of unlawful attacks on his honor or reputation.
- 3 Everyone has the right to the protection of the **law** against such interference or attacks.

[n113](#) For example, the U.N. Human Rights Committee, which is the treaty-monitoring body for the ICCPR, stated in *Coeriel and Aurik v. Netherlands* that the notion of privacy refers to the sphere of a person's life where they can freely express their identity. NIHAL JAYAWICKRAMA, THE JUDICIAL APPLICATION OF HUMAN RIGHTS **LAW: NATIONAL, REGIONAL AND INTERNATIONAL JURISPRUDENCE** 608, 604 (2002) (citing *Coeriel and Aurik v. Netherlands*, U.N. Hum. Rts. Comm. Communication No. 453/1991, U.N. Doc. CCPR/C/52/D/453/1991 (1994)).

[n114](#) See INTERIGHTS, NON-DISCRIMINATION IN **INTERNATIONAL LAW: A HANDBOOK FOR PRACTITIONERS** 256 (Kevin Kitching ed., 2005), available at <http://www.interights.org/doc/Handbook.pdf> (providing a comprehensive overview of nondiscrimination rights and the intersection with privacy and equality rights).

[n115](#) *CCPR General Comment No. 16 on Art. 17*, U.N. Human Rights Committee, 32d Sess., Annex 6, U.N. Doc. A/U3/40 (1988) available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/23378a8724595410c12563ed004aeecd?OpenDocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/23378a8724595410c12563ed004aeecd?OpenDocument) (referencing Article 17 of the ICCPR regarding the "right to respect of privacy, family, home and correspondence, and protection of honour and reputation").

[n116](#) See, e.g., JAYAWICKRAMA, *supra* note 113, at 608. According to Jayawickrama:

Respecting the confidentiality of medical data is crucial not only to respect the privacy of the patient, but also to preserve his or her confidence in the medical profession and in the health service in general. It is incompatible with respect for this right for the contents of a psychiatric report to be used, without permission, for a purpose other than that for which it was prepared.

Id. In support of this statement, Jayawickrama quotes the European Court:

These considerations are especially valid as regards protection of the confidentiality of information about a person's HIV infection. Although the interests of a patient and the community as a whole in protecting confidentiality of medical data may be outweighed by the interest in investigation and prosecution of crime and in the publicity of court proceedings, (i) an order to make the transcripts of evidence given by medical advisers and medical records accessible to the public after ten years did not correspond to the wishes or interests of the litigants in the proceedings, all of whom had requested a longer period of confidentiality, and was not supported by reasons which could be considered sufficient to override the patient's interests in the data remaining confidential for a longer period, and therefore amounted to a disproportionate interference with ECHR 8, and (ii) the disclosure of the patient's identity in the judgment was not supported by cogent reasons. *Id.* at 608 n.42 (citing *Z. v. Finland*, 25 E.H.R.R. 371 (1997)).

[n117](#) For more discussion of state obligations to respect privacy and family life, including relevant ECHR jurisprudence, see INTERIGHTS, *supra* note 114, at 259-62.

[n118](#) UDHR, *supra* note 104. See *id.* art. 7: "All are equal before the **law** and are entitled without any discrimination to equal protection of the **law**. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination." See also ICCPR, *supra* note 108, art. 2:

1 Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subject to its jurisdiction the rights recognized in the present Covenant, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status; . . . *Id.* art. 26:

All persons are equal before the **law** and are entitled without any discrimination to the equal protection of the **law**. In this respect, the **law** shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status; . . .

ICESCR, *supra* note 109, art. 2: "2. The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, birth or other status." For regional instruments, see the European Convention for the Protection of Human Rights and Fundamental Freedoms, *opened for signature* Nov. 4, 1950, art. 14, 213 U.N.T.S. 222 (entered into force Sept. 3, 1953): "The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status" and the American Declaration of the Rights and Duties of Man, O.A.S. Res. XXX, adopted by the Ninth **International** Conference of American States (1948), *reprinted in* Basic Documents Pertaining to Human Rights in the Inter-American System, OEA/Ser.L.V/II.82 doc.6 rev.1 at 17 (1992). See, *e.g.*, *id.* art. 2: "All persons are equal before the **law** and have the rights and duties established in this Declaration, without distinction as to race, sex, language, creed or any other factor"; The American Convention on Human Rights, Nov. 21, 1969, O.A.S. Treaty Series No. 36, 1144 U.N.T.S. 123:

Article 1

1 The States Parties to this Convention undertake to respect the rights and freedoms recognized herein and to ensure to all persons subject to their jurisdiction the free and full exercise of those rights and freedoms, without any discrimination for reasons of race, color, sex, language, religion, political or other opinion, national or social origin, economic status, birth, or any other social condition . . .

Article 24

All persons are equal before the **law**, consequently, they are entitled without discrimination, to equal protection of the **law**;

African [Banjul] Charter on Human and Peoples' Rights, *adopted* June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982).

Article 2

Every individual shall be entitled to the enjoyment of the rights and freedoms recognized and guaranteed in the present Charter without distinction of any kind such as race, ethnic group, color, sex, language religion, political or any other opinion, national and social origin, fortune, birth or other status.

Article 3

1 Every individual shall be equal before the **law**.

2 Every individual shall be entitled to equal protection of the **law**.

[n119](#) See JAYAWICKRAMA, *supra* note 113, at 174. Also on this point, notions of equality have evolved considerably in the discourse on **international** disability rights. Distinctions between formal and substantive equality are highly relevant. For a comprehensive overview of this discussion, see THERESIA DEGENER & GERALD QUINN, A SURVEY OF **INTERNATIONAL**, COMPARATIVE AND REGIONAL DISABILITY **LAW** REFORM (2000), available at http://www.dredf.org/international/degener_quinn.html, and INTERRIGHTS, *supra* note 114, at 19-22.

[n120](#) **International** Labour Organization Discrimination (**Employment** and Occupation) Convention (ILO No. 111) June 25, 1958, 362 U.N.T.S. 31 U.N. Doc 1/5181 (entered into force June 16, 1960) [hereinafter ILO Convention]. The relevant text of the ILO Convention includes the following excerpts from the preamble and Article 1, which are relevant in the discussion of protecting against genetic discrimination in the workplace:

Having determined that these proposals shall take the form of an **international** Convention, and

Considering that the Declaration of Philadelphia affirms that all human beings, irrespective of race, creed or sex, have the right to pursue both their material well-being and their spiritual development in conditions of freedom and dignity, of economic security and equal opportunity, and

Considering further that discrimination constitutes a violation of rights enunciated by the Universal Declaration of Human Rights, adopts the twenty-fifth day of June of the year one thousand nine hundred and fifty-eight, the following Convention, which may be cited as the Discrimination (**Employment** and Occupation) Convention, 1958:

Article 1

1 For the purpose of this Convention the term *discrimination* includes --

(a) any distinction, exclusion or preference made on the basis of race, colour sex, religion, political opinion, national extraction or social origin, which has the effect of nullifying or impairing equality of opportunity or treatment in **employment** or occupation;

(b) such other distinction, exclusion or preference which has the effect of nullifying or impairing equality of opportunity or treatment in **employment** or occupation as may be determined by the Member concerned after consultation with representative employers' and workers' organisations, where such exist, and with other appropriate bodies.

2 Any distinction, exclusion or preference in respect of a particular job based on the inherent requirements thereof shall not be deemed to be discrimination.

3 For the purpose of this Convention the terms **employment** and *occupation* include access to vocational training, access to **employment** and to particular occupations, and terms and conditions of **employment**.

Id. pmb., art. 1.

[n121](#) UNESCO is the United Nations Economic, Social and Cultural Organization, established in 1945 and comprising 189 member states and 6 associate members. See UNESCO, *About UNESCO*, available at http://portal.unesco.org/en/ev.php-URL_ID=3328&URL_DO=DO_TOPIC&URL_SECTION=201.htm1 (last visited Sept. 3, 2005). All APEC and OECD members are members of UNESCO except for the United States. See *id.* UNESCO's Constitution adopted in November 1945 requires the organization to "further universal respect for justice, for the rule of **law** and for human rights and fundamental freedoms." See UNESCO, *About UNESCO: Constitution of UNESCO* available at http://portal.unesco.org/en/ev.php-URL_ID=6206&URL_DO=DO_TOPIC&URL_SECTION=201.html (last visited Sept. 3, 2005). In 2002, UNESCO made ethics one of the top five priorities of the organization. See UNESCO, *UNESCO's Priorities (2002-2003)*, available at http://portal.unesco.org/en/eu.php-URL_ID=6206&URL_DO=DO_TOPIC&URL_Section=201html

[n122](#) Universal Declaration on the Human Genome and Human Rights, UNESCO Gen. Conf. Res. 29 C/Resolution 16, Article 6, *reprinted in* Records of the General Conference, UNESCO, 29th Sess., 29 C/Resolution 19, at 41 (1997) (adopted by the U.N. General Assembly, G.A. Res. 152, U.N. GAOR, 53rd Sess., U.N. Doc. A/RES/53/152 (1999)) [hereinafter UNESCO Declaration].

[n123](#) Declarations are another means of defining norms, which are not subject to ratification. Like recommendations, they set forth universal principles to which the community of States wished to attribute the greatest possible authority and to afford the broadest possible support. Many examples might be provided as authority, the first being the Universal Declaration of Human Rights that was adopted on December 10, 1948 by the United Nations General Assembly. See UDHR, *supra* note 104. As in the case of the United Nations Charter, UNESCO's Constitution does not include declarations among the proposals which may be submitted to the General Conference for adoption. See UNESCO, *About UNESCO: Constitution of UNESCO*, available at http://portal.unesco.org/en/ev.php-URL_ID=6206&URL_DO=DO_TOPIC&URL_SECTION=201.html (last visited Sept. 2, 2005). However, the General Conference would seem to be entitled to give a document submitted to it for consideration and adoption the form of a declaration that has its own particular scope, and has indeed already done so on several occasions in the past. See UNESCO, *General Introduction to the Standard-Setting Instruments of UNESCO*, available at http://portal.unesco.org/unesco/ev.php?URL_ID=23772&URL_DO=DO_TOPIC&URL_SECTION=201&reload=1101727325#name=3 (last visited Sept. 3, 2005). In this connection, it is interesting to note the interpretation formulated by the United Nations Legal Adviser in 1962, in response to the request of the Commission on Human Rights, regarding the Universal Declaration of Human Rights:

In United Nations practice, a "declaration" is a formal and solemn instrument, suitable for rare occasions when principles of great and lasting importance are being enunciated, such as the Declaration of Human Rights. A recommendation is less formal.

Apart from the distinction just indicated, there is probably no difference between a "recommendation" and a "declaration" in United Nations practice as far as strict legal

principle is concerned. A "declaration" or a "recommendation" is adopted by resolution of a United Nations organ. As such it cannot be made binding upon member States, in the sense that a treaty or convention is binding upon the parties to it, purely by the device of terming it a "declaration" rather than a "recommendation." However, in view of the greater solemnity and significance of a "declaration," it may be considered to impact, on behalf of the organ adopting it, a strong expectation that Members of the **international** community will abide by it. Consequently, in so far as the expectation is gradually justified by State practice, a declaration may by custom become recognized as laying down Rules binding upon States.

In conclusion, it may be said that in United Nations practice, a "declaration" is a solemn instrument resorted to only in very rare cases relating to matters of major and lasting importance where maximum compliance is expected.

Id. (quoting *Report of the Commission on Human Rights*, Econ. and Social Council, 18th Sess., U.N. Doc. E/3616/Rev. 1 (1962)).

[n124](#) UNESCO Declaration, *supra* note 122, art. 5(b).

[n125](#) *Id.* art. 5(c).

[n126](#) *Id.* art. 7.

[n127](#) **International** Declaration on Human Genetic Data, UNESCO Gen. Conf. Res. 33 C/Resolution 22, *reprinted in* Records of the General Conference, UNESCO, 33rd Sess., 29 C/Resolution 19, at 39 (2003) [hereinafter **International** Declaration].

[n128](#) *Id.* For example, the **International** Declaration notes in the preamble that: "the collection, processing, use and storage of human genetic data have potential risks for the exercise and observance of human rights and fundamental freedoms and respect for human dignity," and that "the interests and welfare of the individual should have priority over the rights and interests of society and research." It "reaffirm[s]":

the principles established in the Universal Declaration on the Human Genome and Human Rights and the principles of equality, justice, solidarity and responsibility as well as respect for human dignity, human rights and fundamental freedoms, particularly freedom of thought and expression, including freedom of research, and privacy and security of the person, which must underlie the collection, processing, use and storage of human genetic data.

Id. pmb. Articles 8 and 9, respectively, provide for the consent and withdrawal of consent by an individual for the collection and use of genetic information. *Id.* art. 8 & 9. Article 10 upholds the right of an individual not to be informed of the results of genetic information collected for medical or scientific purposes. *Id.* art. 10. Article 14 sets out principles regarding confidentiality and privacy. *Id.* art. 14.

[n129](#) See **International** Declaration, *supra* note 127 art. 1 (entitled Aims and scope):

(a) The aims of this Declaration are: to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, human proteomic data and of the biological samples from which they are derived, referred to hereinafter as "biological samples," in keeping with the

requirements of equality, justice and solidarity, while giving due consideration to freedom of thought and expression, including freedom of research; to set out the principles which should guide States in the formulation of their legislation and their policies on these issues; and to form the basis for guidelines of good practices in these areas for the institutions and individuals concerned.

(b) Any collection, processing, use and storage of human genetic data, human proteomic data and biological samples shall be consistent with the **international law** of human rights.

(c) The provisions of this Declaration apply to the collection, processing, use and storage of human genetic data, human proteomic data and biological samples, except in the investigation, detection and prosecution of criminal offences and in parentage testing that are subject to domestic **law** that is consistent with the **international law** of human rights.

[n130](#) See *id.* art. 14 (entitled Privacy and confidentiality):

(a) States should endeavour to protect the privacy of individuals and the confidentiality of human genetic data linked to an identifiable person, family or, where appropriate, group, in accordance with domestic **law** consistent with the **international law** of human rights.

(b) Human genetic data, human proteomic data and biological samples linked to an identifiable person should not be disclosed or made accessible to third parties, in particular, employers, insurance companies, educational institutions and the family, except for an important public interest reason in cases restrictively provided for by domestic **law** consistent with the **international law** of human rights or where the prior, free, informed and express consent of the person concerned has been obtained provided that such consent is in accordance with domestic **law and the international law** of human rights. The privacy of an individual participating in a study using human genetic data, human proteomic data or biological samples should be protected and the data should be treated as confidential.

(c) Human genetic data, human proteomic data and biological samples collected for the purposes of scientific research should not normally be linked to an identifiable person. Even when such data or biological samples are unlinked to an identifiable person, the necessary precautions should be taken to ensure the security of the data or biological samples.

(d) Human genetic data, human proteomic data and biological samples collected for medical and scientific research purposes can remain linked to an identifiable person, only if necessary to carry out the research and provided that the privacy of the individual and the confidentiality of the data or biological samples concerned are protected in accordance with domestic **law**.

(e) Human genetic data and human proteomic data should not be kept in a form which allows the data subject to be identified for any longer than is necessary for achieving the purposes for which they were collected or subsequently processed.

[n131](#) For more information on UNESCO and the **International** Bioethics Committee, and the Draft Universal Norms on Bioethics, see UNESCO, *Preliminary Draft Declaration on Universal Norms on Bioethics at*

http://portal.unesco.org/shs/en/file_download.php/101d16a8d802caebf882673e4443950fdpreliminary_Draft_EW.pdf

[n132](http://portal.unesco.org/shs/en/ev.php-URL_ID=1879&URL_DO=DO_TOPIC&URL_SECTION=201.html) UNESCO, **International** Bioethics Committee (IBC), available at http://portal.unesco.org/shs/en/ev.php-URL_ID=1879&URL_DO=DO_TOPIC&URL_SECTION=201.html (last visited May 24, 2005).

UNESCO's **International** Bioethics Subcommittee is a committee of 36 independent experts with a mandate:

1. To promote reflection on the ethical and legal issues raised by research in the life sciences and their applications and to encourage the exchange of ideas and information, particularly through education;
2. To encourage action to heighten awareness among the general public, specialized groups and public and private decision-makers involved in bioethics;
3. To co-operate with the **international** governmental and non-governmental organizations concerned by the issues raised in the field of bioethics as well as with the national and regional bioethics committees and similar bodies;
- 4 (i) To contribute to the dissemination of the principles set out in the Universal Declaration on the Human Genome and Human Rights, and to the further examination of issues raised by their applications and by the evolution of the technologies in question; (ii) to organize appropriate consultations with stakeholders;
- (iii) to make recommendations addressed to the General Conference, to give advice concerning the follow-up of the Declaration, and to identify practices that could be contrary to human dignity.

Id.

[n133](http://portal.unesco.org/shs/en/file_download.php/48ac231eee2ac5bbd52491a23512a2f3STATCIBA.pdf) In accordance with Article 11 of the Statutes of the **International** Bioethics Committee (IBC), the Intergovernmental Committee examines the advice and recommendations of the IBC, including those concerned with the follow-up of the Universal Declaration. See UNESCO, STATUTES OF THE **INTERNATIONAL** BIOETHICS COMMITTEE (IBC) art. 11, available at http://portal.unesco.org/shs/en/file_download.php/48ac231eee2ac5bbd52491a23512a2f3STATCIBA.pdf (last visited Sept. 3, 2005). It informs the IBC of its opinions. See *id.* It submits its opinions to the Director-General for transmission, together with the advice and recommendations of the IBC, to the Member States, the Executive Board and the General Conference. See *id.* It may transmit any proposals for the follow-up of the advice and recommendations of the IBC. See *id.*

[n134](http://portal.unesco.org/shs/en/file_download.php/10d16a8d802caebf882673e4443950fdPreliminary_Draft_EN.pdf) UNESCO, **INTERNATIONAL** BIOETHICS COMMITTEE, PRELIMINARY DRAFT DECLARATION ON UNIVERSAL NORMS ON BIOETHICS (2005), available at http://portal.unesco.org/shs/en/file_download.php/10d16a8d802caebf882673e4443950fdPreliminary_Draft_EN.pdf (last visited Sept. 3, 2005) [hereinafter Draft Universal Norms]. The Draft Universal Norms were brought about after the meeting of the UNESCO General Conference, at its 32nd session in October 2003, where it was considered "opportune and desirable to set universal standards in the field of bioethics with due regard for human dignity and human rights and freedoms, in the spirit of cultural pluralism inherent in bioethics." UNESCO, *Towards a Declaration on Universal Norms on Bioethics*, at http://portal.unesco.org/shs/en/ev.php-URL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html (last visited Sept. 3, 2005) (quoting 32 C/Res. 24).

[n135](#) See Draft Universal Norms, *supra* note 134, art. 4:

Article 4 -- Human Dignity and Human Rights

- a) Any decision or practice shall be made or carried out with full respect for the inherent dignity of the human person, human rights and fundamental freedoms;
- b) Any decision or practice shall respect the principle that the interests and welfare of the human person prevail over the sole interest of science or society.

[n136](#) See *id.* art. 6: "Article 6 -- Benefit and Harm. Any decision or practice shall seek to benefit the person concerned and to minimize the possible harm resulting from that decision or practice."

[n137](#) See *id.* art. 8:

Article 8 -- Non-Discrimination and Non-Stigmatization

In any decision or practice, no one shall be subjected to discrimination based on any grounds intended to infringe, or having the effect of infringing, the human dignity, human rights or fundamental freedoms of an individual, nor shall such grounds be used to stigmatize an individual, a family, a group or a community.

[n138](#) See *id.* art. 9: "Article 9 -- Autonomy and Individual Responsibility. Any decision or practice shall respect the autonomy of persons to make decisions and to take responsibility for those decisions while respecting the autonomy of others." See *also id.* art. 10 (addressing informed consent and pointing out that Articles 9 and 10 are connected as consent and personal autonomy are interlinked).

[n139](#) For example, there is concern that in the United States, antiterrorism measures are adopted in a manner that infringes **international** human rights **law** guarantees, while simultaneously heralding the virtues of human dignity. Julie Mertus, *Mightier than the Sword: The Bush Administration's Flagging Human Rights Rhetoric*, 25 HARV. INT'L L. J. 84 (2003), available at <http://hir.harvard.edu/articles/1107/> (last visited Sept. 3, 2005). Professor Mertus argues that:

The Bush administration's clearest articulation of human rights policy can be found in the National Security Strategy, a 31-page report that President Bush submitted to the US Congress at the end of September 2002. This comprehensive restatement of US foreign policy made headlines for its endorsement of pre-emptive military action and its support for unilateral US actions in place of **international** treaties and organizations. Equally troubling for those who support multilateral approaches to security and safeguarding justice is the document's replacement of human rights with the watery notion of "human dignity."

The National Security Strategy specifies "aspirations for human dignity" as a primary tenet of US foreign policy. "Aspirations of human dignity," however, do not go far enough. The invocation of "human dignity" instead of "human rights," if accepted and repeated elsewhere, may overturn 50 years of progress in **international law**. The National Security Strategy is peppered with a handful of references to human rights, but human dignity has prime billing. The White House's message is clear: the United States does not seek to champion human rights, but instead promotes an abstract substitute. The **international**

community would agree that "aspirations for human dignity" are important, but insufficient as foreign policy goals. The National Security Strategy reflects at best a misguided application of the terms "human rights" and "human dignity" and, at worst, a deliberate attempt to distort and manipulate them.

Id.

[n140](http://conventions.coe.int/treaty/en/treaties/html/164.htm) European Convention on Human Rights and Biomedicine, Apr. 4, 1997, CETS No. 164, available at <http://conventions.coe.int/treaty/en/treaties/html/164.htm> (last visited Sept. 3, 2005) [hereinafter EU Convention]. Thirty-two countries are signatories to the convention. The preamble to the EU Convention also enshrines the need to protect human dignity as follows: "Convinced of the need to respect the human being both as an individual and as a member of the human species and recognizing the importance of ensuring the dignity of the human being; Conscious that the misuse of biology and medicine may lead to acts endangering human dignity. . . ." *Id.* pmbl.

[n141](#) See *supra* notes 120, 127.

[n142](#) Council of Europe, *Summary of the Convention on Human Rights and Biomedicine* para. 1, available at <http://conventions.coe.int/Treaty/en/Summaries/Html/164.htm> (last visited Sept. 4, 2005).

[n143](#) EU Convention, *supra* note 140. Article 11 provides that: "Any form of discrimination against a person on grounds of his or her genetic inheritance is prohibited." *Id.* art. 11; see also *id.* art. 12:

Article 12 -- Predictive genetic tests

Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counseling; and Article 13: "Article 13 -- Interventions on the human genome. An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants."

[n144](#) Europa, *EU Presidency Statement -- Discrimination and Genetic Privacy* (July 24, 2001) (Statement of Jean-Paul Charlier, Rep. of Belgium), available at http://europa-eu-un.org/articles/et/article_180_et.htm (last visited Sept. 3, 2005). The statement also included the following:

The Universal Declaration on the Human Genome and Human Rights, adopted at the 29th session of UNESCO's General Conference, on 11 November 1997, proclaims in particular that respect for human dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity. The Declaration stipulates that no one must be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity. The European Union takes this opportunity to pay tribute to the pioneering work undertaken by the **International** Bioethics Committee, including work on privacy and prevention of discrimination.

Id.

[n145](#) For example, a State that has ratified the ICCPR is obligated to implement protection of the rights contained in the ICCPR. See ICCPR, *supra* note 108. **International law** is also binding if the right enjoys status as a customary norm, or *jus cogens* -- for example, the right to be free from torture is considered *jus cogens* -- although this may not apply to the human rights triggered in the genetic privacy discussion. *Id.*

[n146](#) For example, [RESTATEMENT \(THIRD\) OF FOREIGN RELATIONS LAW OF THE UNITED STATES § 111\(1\)](#) (1987) states that "**international law and international** agreements of the United States are the **law** of the United States." However, the United States has frequently decided that implementing domestic legislation is required and that **international law** treaties are not self-executing.

[n147](#) For a more thorough discussion of this concept, see Robert Howse, *Mainstreaming the "Right to Development" Into International Trade Law and Policy the WTO (2004)*, at 13-15, available at <http://www.southcentre.org/info/southbulletin/bulletin85/bulletin85-02.htm>. For example, Professor Howse writes:

Alternately or additionally, however, **law** may affect behavior through shaping or reshaping norms -- through the construction or reconstruction of social meanings, which influence social agents' views of themselves and the world, and therewith, the conduct of those agents.¹⁴⁷ This function of **law** may or may not depend upon the existence of centralized coercive authority. Indeed, the very notion of **law** as *legitimate* coercion, and thus as phenomenologically distinct from other kinds of *Gewalt* (Max Weber/Walter Benjamin/Alexandre Kojève), implies that even coercive **law** owes its compliance pull to something other than coercion alone.

Since, so far, **international law** lacks centralized coercive authority, and since lawmakers can only control or determine to a limited extent the existence of sanctions and incentives as a substitute for centralized coercion, one would predict that the substance of **international law** will be somewhat different from that of other forms of **law**. **International law** will be more likely to contain rules, rights, standards (and other juridical material) *capable* of influencing behavior *without* centralized coercion, i.e., through the norm-shaping process, *and also* more likely to contain juridical material that, for various reasons, would be largely *unsuitable* to being enforced directly or immediately through centralized coercion.

Id. at 14.

[n148](#) See *infra* Part VI (comparing the privacy and nondiscrimination protections related to genetic information for employees in the EU and the United States).

[n149](#) Government employees have additional privacy rights that arise from federal or state constitutions or civil service statutes. See *supra* note 80 and accompanying text. Federal government employees are also protected from genetic discrimination by Executive Order 13145. See *infra* note 207 and accompanying text (discussing Executive Order 13145).

[n150](#) U.S. **law** contains:

Very few specific legislative data privacy safeguards. Most existing legislation does not address **employment** relationships, but regulates those between business and consumer or citizen and government. The U.S. concept of a legally enforceable "right to privacy" has expanded slowly. Congress has rejected most attempts to pass comprehensive legislation regulating the treatment of personal data by individuals and businesses in the private sector. The courts are likely to rely on clearly established and articulated state common, statutory, or constitutional **law** in finding a right of privacy. Americans prefer a regime of industry self-regulation without significant government intervention. Barbara Crutchfield George et al., *U.S. Multinational Employers: Navigating Through the "Safe Harbor" Principles to Comply with the EU Data Privacy Directive*, [38 AM. BUS. L.J. 735, 746-48 \(2001\)](#).

[n151](#) The common **law** privacy tort that is most frequently applied to workplace privacy issues is the tort of intrusion into seclusion or into employees' private affairs. See Rothstein, *supra* note 88, at 405-06. If an employer intentionally intrudes, physically or otherwise, upon the solitude or seclusion of the employee in his private affairs or concerns, and a reasonable person would find the intrusion was highly offensive, the employee may be able to recover damages for invasion of privacy under tort **law**. *Id.* Some employees have been successful in workplace privacy lawsuits that are based on privacy tort theories in contexts such as employee drug testing, searching employee work areas, and workplace surveillance. *See id.*

[n152](#) *See supra* note 4; *infra* note 172 and accompanying text for a discussion of the ADA case filed against Burlington Northern Santa Fe Railway related to preemployment genetic testing. *See Roche, supra* note 4, at 272 (commenting that no court has had the opportunity to rule on the applicability of the ADA to a genetic discrimination claim, although the EEOC has taken the position that the ADA does encompass such claims). The EEOC sought an injunction in the *Burlington* case upon receiving complaints from Burlington Northern Santa Fe Railway's employees that the company had been secretly testing their DNA. *Id.* The Railway agreed to cease its genetic testing before it became necessary for the court to rule on the applicability of the ADA to the Railway workers' complaints. *Id.*

[n153](#) [Doe v. High-Tech Inst., Inc., 972 P.2d 1060, 1064 \(Colo. Ct. App. 1998\)](#).

[n154](#) [Id. at 1065-66](#).

[n155](#) [Id. at 1071](#) (holding "an unauthorized HIV test, under the circumstances as set forth in plaintiff's complaint, would be considered by a reasonable person as highly invasive, and therefore, such is sufficient to constitute an unreasonable or offensive intrusion"). The *Doe* court stated: "There is a generally recognized privacy interest in a person's body. Because personal information concerning a person's health may be obtained through one's blood, urine and other bodily products, such products cannot be extracted from a person or initially tested without either consent or proper authorization." [Id. at 1068](#) (citing [Skinner v. Ry. Labor Executives' Ass'n, 489 U.S. 602 \(1989\)](#), a Fourth Amendment case which held that the taking of bodily fluid for analysis is a separate privacy intrusion from the subsequent testing of that fluid).

[n156](#) *Doe* had previously recovered a judgment under this tort theory. [Doe, 972 P.2d at 1064](#).

[n157](#) *Id.*

[n158 *Norman-Bloodsaw*, 135 F.3d at 1269-70.](#)

[n159](#) The Ninth Circuit held that under the Federal Constitution there is a generally recognized privacy interest in information concerning one's health and genetic information. *Id.* (holding that testing government employees' bodily fluids for pregnancy, syphilis, and sickle-cell trait implicated federally protected privacy rights under the Constitution). Generally, private-sector employees have no federal constitutional privacy rights with respect to their employers' actions. See Elbert Lin, *Prioritizing Privacy: A Constitutional Response to the Internet*, [17 BERKELEY TECH. L.J. 1085, 1150 \(2002\)](#) ("The federal constitution is firmly entrenched in the concept that constitutional rights apply only against state actors."); see also Daniel J. Solove, *Privacy and Power: Computer Databases and Metaphors for Information Privacy*, [53 STAN. L. REV. 1393, 1435 \(2001\)](#). Only one state, California, has a state constitution that protects employee privacy from employer intrusions in private-sector workplaces. See CAL. CONST. art. I, § 1; [Porten v. Univ. of San Francisco](#), [64 Cal. App. 3d 825, 829 \(Cal. Ct. App. 1976\)](#) (holding that there is a state constitutional right of privacy for public and private employees).

[n160 *Norman-Bloodsaw*, 135 F.3d at 1269-70.](#)

[n161 *Id.*](#)

[n162 *Id.* at 1270.](#)

[n163 *Board of Med. Quality Assurance v. Gherardini*, 93 Cal. App. 3d 669, 679-81 \(Cal. Ct. App. 1979\)](#) (recognizing a right to privacy in an individual's medical records such that medical information generally cannot be released by a physician without a patient's consent and authorization); see also Fedder, *supra* note 13, at 572-74.

[n164](#) See Fedder, *supra* note 13, at 572-74; see also [Bratt v. Int. Bus. Mach. Corp.](#), [467 N.E.2d 126, 129 \(Mass. 1984\)](#) (holding that the unauthorized disclosure of medical information to a third party, such as an employer, is not tortious if the employer has a substantial and valid interest in obtaining relevant medical information about an employee).

[n165](#) For a discussion of the limited U.S. federal legislation that protects the privacy of employees' personal medical information, see *infra* notes 167-98 and accompanying text.

[n166](#) ADA, *supra* note 18.

[n167](#) [42 U.S.C. § 12101\(5\)](#), 1211 2(a).

[n168](#) [42 U.S.C. § 12102\(2\)](#); see also U.S. Equal **Employment** Opportunity Commission, *Section 902 Definition of Disability: Addendum*, available at <http://www.eeoc.gov/policy/docs/902cm.html> (last modified Feb. 1, 2000) (summarizing recent interpretations of the definition of disability found in U.S. Supreme Court cases).

[n169](#) The ADA requires employers to keep information collected about employees' medical conditions including medical history, on separate forms and in separate confidential medical files. [42 U.S.C. § 12112\(d\)\(3\)](#). It also prohibits disclosure of confidential medical information except for specific job-related reasons related to making necessary medical restrictions to job duties, making reasonable accommodation, anticipating emergency assistance, or to government investigators. *Id.* See also EEOC, *Enforcement Guidance: Disability-Related Inquiries and Medical Examinations of Employees Under the Americans with Disabilities Act*, July 27, 2000, at nn.13-15, available at

<http://www.eeoc.gov/policy/docs/guidance-inquiries.html> [hereinafter EEOC, *Enforcement Guidance on Disability-Related Inquiries*]; EEOC, *Enforcement Guidance: Preemployment Disability-Related Questions and Medical Examinations Under the Americans with Disabilities Act*, Oct. 10, 1995 [hereinafter EEOC, *Preemployment Questions and Medical Examinations*], available at <http://www.eeoc.gov/policy/docs/preemp.html>.

n170 See Yesley, *supra* note 34, at 654 (reporting that "the ADA does not specifically mention genetics but clearly covers expressed genetic disorders to the same extent as impairments without a genetic component. Whether the ADA also covers unexpressed genetic predispositions and recessive traits is, however, unclear").

n171 *Id.* ("The EEOC has taken the position that the ADA covers a genetic predisposition that is regarded as an impairment by the employer."); see also EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at n.21 and accompanying text. As used in this guidance, the term "genetic information" has the same definition as "protected genetic information" in Executive Order 13145. *Id.* See also *infra* note 207. "In general, genetic information is information about an individual's genetic tests, information about the genetic tests of an individual's family members, or information about the occurrence of a disease, medical condition, or disorder in family members of the individual." EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra*, at n.21; see also *infra* note 207 and accompanying text.

n172 Press Release, EEOC, EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing under Americans with Disabilities Act (Feb. 9, 2001), available at <http://www.eeoc.gov/press/2-9-01-c.html> (reporting the filing of the EEOC's first court action challenging genetic testing by an employer and seeking a preliminary injunction against Burlington Northern Santa Fe Railroad (BNSF)); Press Release, EEOC, EEOC Settles ADA Suit Against BNSF for Genetic Bias (Apr. 18, 2001), available at <http://www.eeoc.gov/press/4-18-01.html> (reporting a settlement of the EEOC's lawsuit seeking a preliminary injunction against BNSF; Press Release, EEOC, EEOC and BNSF Settle Genetic Testing Case under Americans with Disabilities Act (May 8, 2002), available at <http://www.eeoc.gov/press/5-8-02.html> (reporting a mediated settlement for \$ 2.2 million of the EEOC lawsuit which alleged that BNSF violated the ADA by genetically testing or seeking to test at least 36 of its employees without their knowledge or consent as part of a diagnostic medical examination related to the employees' claims or internal reports of work-related carpal tunnel syndrome injuries).

n173 [42 U.S.C. § 12112\(a\)](#)(2005).

n174 See *supra* notes 40-42 and accompanying text. Title VII of the Civil Rights Act of 1964 prohibits employer discrimination on the basis of race, color, sex, national origin, and religion and has been used to challenge some forms of genetic discrimination in the workforce. See [42 U.S.C. § 2000e](#) to 2000e-17 (2005) [hereinafter Title VII]; [Norman-Bloodsaw v. Lawrence Berkeley Lab.](#), [135 F.3d 1260, 1272 \(9th Cir. 1998\)](#) (holding that the employer's practice of testing only Black employees for sickle cell trait violated Title VII). Title VII may be applicable to genetic discrimination when an employer screens all employees for a particular genetic trait that is closely associated with a particular racial or ethnic group, such as sickle cell disease which occurs more frequently among African Americans than among other groups, or TaySachs disease that appears more frequently among those of Ashkenazi Jewish ancestry. Kim, *supra* note 13, at 1512-13. However, to prevail on a Title VII claim, the employee must be able to prove that the genetic criterion was a pretext for intentional discrimination against the affected group or that the test had a statistically significant impact on the job opportunities of a protected class. See *id.*

[n175](#) See EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at n.29. "A medical examination' is a procedure or test that seeks information about an individual's physical or mental impairments or health." *Id.* See also EEOC, *Policy Guidance on Executive Order 13145*, *supra* note 211 (giving the EEOC's definition of genetic information, which includes information about a person's genetic tests).

[n176](#) See Tara Pepper, *Inside the Head of an Applicant*, NEWSWEEK, Feb. 21, 2005, at E24 (reporting the role of genes in setting the range of personality traits a person may develop and the potential for genetic tests to be developed that will reveal gene-related personality traits of job applicants for employee selection purposes).

[n177](#) See *id.* Pepper reports that businesses are interested in genetic research by scientists that relates to personality because it may help predict a person's personality traits for purposes of employee selection:

Two different forms of one gene regulate serotonin, a neurotransmitter associated with mood and emotional stability. One is short and one long, and every individual has two copies of the gene -- one from each parent. Those with two short copies are more likely to be neurotic, anxious and risk-averse.

Id. at E26. Personality tests of this nature would likely be characterized as medical tests under the ADA's medical examination rules. See *infra* note 178 and accompanying text.

[n178](#) See Lasprogata et al., *supra* note 15, at P 80, tables 1 & 3 (providing comparative summary of the EU, U.S., and Canadian regulation protecting personal data, including discussion of personal data protection related to employees' medical information and the ADA).

[n179](#) See *id.*; see also Privacy Directive, *supra* note 7, art. 8.

[n180](#) See [42 U.S.C. § 12112\(b\)\(2\)](#) (2005); see also EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169 and accompanying text.

[n181](#) See [42 U.S.C. § 12112\(d\)](#); [42 U.S.C. § 12112\(d\)\(4\)\(C\)](#) (requiring compliance with the ADA's medical confidentiality rules with respect to information about the medical condition or medical history of "any employee" obtained by an employers' inquiries or examinations).

[n182](#) See [42 U.S.C. §§ 12112\(d\), \(d\)\(4\)\(C\)](#); see also *infra* notes 200-07 and accompanying text.

[n183](#) [Leonel v. Am. Airlines, Inc., 400 F.3d 702, 708-11 \(9th Cir. 2005\)](#). In this case, three applicants for flight attendant positions were given job offers by American Airlines before completion of background checks by American Airlines and conditional on the applicants passing a medical examination. *Id.* at 704-05. The applicants were required to complete the medical examination before the background check was completed and in the medical examination were asked questions about their physical condition and medications that they were taking; to answer the questions honestly they would have disclosed their HIV-positive status and treatment for HIV. *Id.* at 706-07. All three applicants did not disclose this information. *Id.* Applicants were given blood tests as part of their medical examinations. *Id.* The results of the blood tests lead to further questions of the applicants and ultimately the applicants disclosed their HIV-positive status to American Airlines. *Id.* at 707. After the

applicants disclosed their HIV-positive status, American Airlines revoked their job offers for nondisclosure of medical information including information about medications the applicants were taking to treat HIV. Leonel at 707-08. The trial court dismissed the applicants' lawsuit for violations of the ADA (and state **law** claims) on summary judgment. *Id.* The Ninth Circuit reversed, remanding the case for trial. *Id.* at 711. The Ninth Circuit held it was a violation of the ADA for American Airlines to require the applicants to disclose medical information and take a medical examination prior to completing the background checks, and that the employer could not lawfully revoke the applicants' conditional job offers for failure to disclose personal medical information about their HIV status prior to receiving a job offer that was conditional only upon medical qualification for the job. *Id.* at 711.

[n184](#) See [42 U.S.C. § 12112\(d\)](#); [29 C.F.R. §§ 1630.13-.14](#) (2005).

[n185](#) [42 U.S.C. § 12112\(d\)](#).

[n186](#) Interpretive Guidance on Title I of the Americans with Disabilities Act, [56 Fed. Reg. 35, 734-35, 753](#) (July 26, 1991) (to be codified at 39 C.F.R. pt. 1630, app.) [hereinafter EEOC's Interpretive Guidance on Title 1 of the ADA] (commenting, in section 1630.13(a), that "an employer cannot inquire as to whether an individual has a disability at the pre-offer stage of the selection process").

[n187](#) [29 C.F.R. § 1630.14](#). At this stage, the employer is permitted to collect disability-related information about applicants, including medical history, but must give the same medical examinations to all applicants in the same job category. [42 U.S.C. § 12112\(d\)\(3\)](#). Post-job offer medical examinations need not be job-related. See 39 C.F.R. § 1630.14(b)(3); EEOC, *Preemployment Questions and Medical Examinations*, *supra* note 169, at n.19 and accompanying text.

[n188](#) [29 C.F.R. § 1630.14\(b\)\(3\)](#); [42 U.S.C. § 12112\(d\)\(3\)](#); EEOC, *Preemployment Questions and Medical Examinations*, *supra* note 169, at n.19 and accompanying text.

[n189](#) See *infra* notes 225-33 and accompanying text for a discussion of state **laws** that may prohibit genetic testing in this context. Although the employer is generally free to conduct a broad array of medical tests and otherwise gather broad medical information about the applicant, the ADA restricts the employer's use of medical information in **employment** decisions when the information does not relate to the applicant's ability to perform the job. Employers are prohibited from using medical information about applicants, including information obtained in a post-job offer medical examination, to discriminate against applicants on the basis of disability. [42 U.S.C. § 12112\(b\)](#); [29 C.F.R. §§ 1630.10, .14\(b\)\(3\)](#).

[n190](#) [42 U.S.C. § 12112\(b\)](#); [29 C.F.R. §§ 1630.10, .14\(b\)\(3\)](#).

[n191](#) [42 U.S.C. § 12112\(b\)\(5\)\(A\)](#).

[n192](#) [42 U.S.C. § 12112\(d\)\(4\)\(B\)](#); [29 C.F.R. § 1630.14\(c\)](#).

[n193](#) EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at n.8 and accompanying text.

[n194](#) EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at n.21 and accompanying text. As used in this guidance, the term "genetic information" has the same definition as "protected genetic information" in Executive Order 13145. *Id.* "In general, genetic information is information about an individual's genetic tests, information

about the genetic tests of an individual's family members, or information about the occurrence of a disease, medical condition, or disorder in family members of the individual." *Id.* See also Executive Order 13145, *infra* note 207 and accompanying text. The ADA also limits the employer's ability to require medical examinations of employees, permitting such examinations only if they are job-related. See EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at n.29 and accompanying text. "A 'medical examination' is a procedure or test that seeks information about an individual's physical or mental impairments or health." *Id.* According to the EEOC, medical examinations include "blood, urine, saliva and hair analyses to detect disease or genetic markers (e.g., for conditions such as sickle cell trait, breast cancer, Huntington's disease)." EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169.

[n195](#) However, state **laws** may prohibit or restrict genetic workplace testing in this context. See *infra* notes 225-33 and accompanying text.

[n196](#) [42 U.S.C. § 12112\(b\)](#). In essence, the ADA prohibits companies from disclosing information about applicants' and employees' medical conditions, physical or mental impairments, and medical treatments to anyone inside the company or outside the company, except when permitted for specified purposes set out in the ADA. See *id.* Employers may share such information only in limited circumstances with supervisors, managers, first aid and safety personnel, and government officials investigating compliance with the ADA. See EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at text accompanying n.10. The ADA's rules related to employee medical information apply even when the medical information is voluntarily provided to the employer by the employee, for example, as part of workplace wellness programs. See *id.*; EEOC, *Enforcement Guidance on Disability-Related Inquiries*, *supra* note 169, at text accompanying n.9.

[n197](#) See [29 C.F.R. § 825.306\(b\)](#) (limiting the amount of information an employer may request to support a leave request); [29 C.F.R. § 825.500\(g\)](#) (requiring that records containing medical information be kept in separate confidential medical files and maintained according to confidentiality requirements of the ADA). See *generally* Family and Medical Leave Act (FMLA) of 1993, [29 U.S.C. §§ 2601-2654](#) (2005).

[n198](#) See *supra* note 169 and accompanying text for a discussion of the ADA's three-prong definition of disability. See also *infra* note 212 and accompanying text for a discussion of the EEOC Policy Guidance on Executive Order 13145.

[n199](#) See [Sutton v. United Air Lines, Inc., 527 U.S. 471 \(1999\)](#); [Murphy v. United Parcel Serv., Inc., 527 U.S. 516 \(1999\)](#); [Albertson's, Inc. v. Kirkingburg, 527 U.S. 555 \(1999\)](#).

[n200](#) See [Sutton, 527 U.S. at 481-93](#) (holding that two sisters with extreme myopia who were not hired were not protected under the ADA; they were not substantially limited in a major life activity due to their use of mitigating measures in the form of corrective lenses); [Murphy, 527 U.S. at 521-25](#) (holding that a mechanic discharged from his job due to his high blood pressure was not actually disabled within the meaning of the ADA because his blood pressure was controllable through medication, nor was he regarded by his employer as disabled); [Albertson's, 527 U.S. at 565-67](#) (holding that a driver with vision in only one eye who was fired when he could not meet a requirement to have vision in two eyes was not protected by the ADA because he had learned to compensate for his vision limitation).

[n201](#) [Sutton, 527 U.S. at 475-76, 481-93.](#)

[n202](#) *Id.*

[n203](#) "Given that everyone is believed to carry some genetic anomalies, the [*Sutton*] Court's reliance on the 43 million figure seems inconsistent with including asymptomatic genetic anomalies in the ADA's definition of disability." Kim, *supra* note 13, at 1528 n.139. In this quotation, Kim is referring to the Supreme Court's reliance in *Sutton* on Congressional findings at the time the ADA was enacted that some 43 million Americans had one or more physical or mental disabilities, and the Court's conclusion that it was therefore inconsistent to determine disability without regard to corrective measures because doing so would increase the coverage of the ADA to a much larger number of Americans. *Id.*

[n204](#) As the Supreme Court stated in *Sutton*:

The Act defines a "disability" as "a physical or mental impairment that *substantially limits* one or more of the major life activities" of an individual. § 12102(2)(A) (emphasis added). Because the phrase "substantially limits" appears in the Act in the present indicative verb form, we think the language is properly read as requiring that a person be presently -- not potentially or hypothetically -- substantially limited in order to demonstrate a disability. A "disability" exists only where an impairment "substantially limits" a major life activity, not where it "might," "could," or "would" be substantially limiting if mitigating measures were not taken. A person whose physical or mental impairment is corrected by medication or other measures does not have an impairment that presently "substantially limits" a major life activity. To be sure, a person whose physical or mental impairment is corrected by mitigating measures still has an impairment, but if the impairment is corrected it does not "substantially limit" a major life activity. [527 U.S. at 482-83.](#)

[n205](#) *Id.*

[n206](#) *Id.*

[n207](#) Exec. Order No. 13145, [65 Fed. Reg. 6,877](#) (Feb. 8, 2000) [hereinafter Executive Order or Executive Order 13145].

[n208](#) *Id.*

[n209](#) *Id.*

[n210](#) PGI is:

1. In general protected genetic information means: A. Information about an individual's genetic tests; B. information about the genetic tests of an individual's family members; or C. information about the occurrence of a disease, or medical condition or disorder in family members of the individual.
2. Information about an individual's current health status (including information about sex, age, physical exams and chemical, blood, or urine analyses) is not protected genetic information unless it is described in subparagraph (1).

Id. § 1-201(e).

[n211](#) See EEOC, *Policy Guidance on Executive Order 13145: To Prohibit Discrimination in*

Federal **Employment** Based on Genetic Information, July 26, 2000, available at <http://www.eeoc.gov/policy/docs/guidance-genetic.html> [hereinafter EEOC, *Policy Guidance on Executive Order 13145*] (stating that "The Executive Order directs Executive departments and agencies to extend the policy of nondiscrimination based on protected genetic information to all its employees"); see also EEOC, *Questions and Answers: EEOC Policy Guidance on Executive Order 13145 Prohibiting Discrimination in Federal Employment Based on Genetic Information*, available at <http://www.eeoc.gov/policy/docs/qanda-genetic.html> (last modified July 27, 2000) (stating that "Individuals employed in the private sector are not covered").

[n212](#) See EEOC, *Policy Guidance on Executive Order 13145*, *supra* note 211.

[n213](#) For example, the EEOC's *Policy Guidance on Executive Order 13145* provides guidance on prohibited adverse **employment** actions, requirements to protect confidentiality of PGI, including limitations on disclosure of PGI, and prohibited processing of PGI in terms of collection and use, with limited exceptions that balance privacy protections and nondiscrimination purposes with valid workplace considerations. See *id.* §§ IV-V.

[n214](#) See *id.* § VII(17)-(19).

[n215](#) See *id.* § VII(18). The EEOC's guidance seems to conflict with the Supreme Court's discussion of the scope of the ADA in [Sutton, 527 U.S. at 482-83](#).

[n216](#) EEOC, *Policy Guidance on Executive Order 13145*, *supra* note 211, § VII(18).

[n217](#) See *id.*; [Sutton, 527 U.S. at 482-83](#) (referencing [Bragdon v. Abbott, 524 U.S. 624, 640-41 \(1998\)](#), in which the Supreme Court held that HIV-positive but asymptomatic persons are protected by the ADA because reproduction is a major life activity). When a person has an impairment that causes a severe or fatal disease that may be transmitted to offspring, that person could be substantially limited in the major life activity of reproduction. [Bragdon, 524 U.S. at 640-41](#). Similarly, persons who do not have genetic diseases, but who carry genetic defects associated with severe or fatal diseases that could be passed to their children may be protected by the ADA because their genetic defect limits the major life activity of reproduction.

[n218](#) [42 U.S.C.S. § 201.1128C](#) (2005). See also *Jendusa*, *supra* note 30, at 179 (explaining that selfinsured health insurance plans may provide coverage to employees through their place of **employment**, and that the employer itself is self-insured, rather than being covered by a group insurance policy). Administrative rules interpreting HIPAA require privacy for "protected health information" (PHI), which is defined as individually identifiable health information. HIPAA Privacy Regulations, [45 C.F.R. §§ 164.102](#), .530 (2005). The privacy protections under HIPAA only apply when a health care provider transmits health care information electronically. Carter Manny, *Privacy Protection for Health Information Transferred between the European Union and the U.S.: A Comparison of Legal Frameworks*, 36 Bus. L. REV. 107, 109-10 (2003). The HIPAA privacy rules cover PHI which is defined as individually identifiable health information, excluding education records and **employment** records held by a covered entity in its role as an employer. *Id.* Under HIPAA rules, the person whose health information is being transferred by a health care provider (including an employee covered by an employer's self-insured plan) is required to give permission for use or disclosure of health care data, unless a statutory exclusion applies. *Id.* at 110.

[n219](#) Manny, *supra* note 218, at 113-14. HIPAA also is a nondiscrimination **law**. It prohibits group health plans from using any health status-related factor, including genetic

information, as a reason to deny or limit eligibility for coverage or for charging an individual more for coverage. Department of Labor, *Genetic Information and the Workplace*, Jan. 20, 1998 at 7-8, available at <http://www.dol.gov/asp/programs/history/herman/reports/genetics.htm>. There are civil and criminal penalties for violating HIPAA, but the employee has no private right of action to recover compensation under HIPAA. Manny, *supra* note 218, at 114.

[n220](#) HIPAA Privacy Regulations, [45 C.F.R. § 164.501](#). Educational records and **employment** records held by a covered entity in their role as employer are specifically excluded from PHI. *Id.* To the contrary, HIPAA only regulates covered entities, such as health plans and health care providers, who transmit health care information in electronic form, although it does apply to self-insured health insurance plans sponsored by employers. See *id.*; Manny, *supra* note 218, at 109. Therefore, HIPAA does not regulate employers' collection or use of PHI to make **employment** decisions, and therefore does not provide privacy for genetic information used in **employment** decisions. HIPAA "does not provide overarching protection from discrimination. The **law** only applies in the insurance context and thus does not address **employment** discrimination." Fedder, *supra* note 13, at 580. However, such use could violate the ADA. See *supra* note 158 and accompanying text.

[n221](#) See Manny, *supra* note 218, at 111.

[n222](#) See *supra* note 221 and accompanying text.

[n223](#) [42 U.S.C. § 12117\(a\)](#) (2005). Technically, employees must file a discrimination complaint with the EEOC and obtain a right-to-sue letter before filing a lawsuit under the ADA. *Id.*; [42 U.S.C. § 2000e-5\(b\)](#) (2005) (requiring the EEOC to investigate complaints of disability discrimination); [42 U.S.C. § 2000e-5\(f\)\(1\)](#) (permitting the filing of a civil action at the conclusion of an investigation when complainant has received notice of the right to file such civil action from the EEOC). The EEOC investigates and conciliates such complaints and eventually issues right-to-sue letters to employees who want to pursue their ADA remedies in court. [42 U.S.C. § 2000e-5](#).

[n224](#) National Conference of State Legislatures, *State Genetics Employment Laws* (2005), at <http://www.ncsl.org/programs/health/genetics/ndiscrim.htm> (last visited Sept. 3, 2005) (providing a summary of genetics **employment laws** including links to relevant state statutes).

[n225](#) See *id.*

[n226](#) *Id.*

[n227](#) See, e.g., Roche, *supra* note 4, at 273-83 (discussing the need to harmonize employer and employee interests in legislative efforts to regulate genetic information and testing); Yesley, *supra* note 34, at 663. M. Pagnattaro, *Genetic Discrimination and the Workplace: Employee's Right to Privacy v. Employer's Right to Know*, [39 AM. BUS. L.J. 139, 171-175 \(2001\)](#).

[n228](#) Roche, *supra* note 4, at 281 (referring to Yesley, *supra* note 34, at 663).

[n229](#) Fedder, *supra* note 13, at 577.

[n230](#) *Id.*

[n231](#) See *supra* notes 225-27 and accompanying text; see also Fedder, *supra* note 13, at 577.

[n232](#) See *id.*

[n233](#) See 2005 Statement of Senator Snowe Introducing S. 306, *supra* note 23 (providing an overview of the Congressional efforts since 1996 to pass federal legislation to regulate privacy and discrimination related to the use of genetic information by employers and insurers).

[n234](#) See *supra* notes 20-21 for a discussion of S. 306 and H.R. 1227.

[n235](#) See S. 306, *supra* note 20, at tit. I. (amending the Employee Retirement Income Security Act (ERISA) of 1974 and the Public Health Service Act to expand the prohibition against discrimination by group health plans and health insurance issuers in the group and individual markets on the basis of genetic information or services: (1) by prohibiting enrollment and premium discrimination based on information about a request for or receipt of genetic services and (2) requiring genetic testing).

[n236](#) See *id.* tit. II.

[n237](#) See *id.* § 2(4) (citing [Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260, 1269 \(9th Cir. 1998\)](#)).

[n238](#) See *id.* § 2(5). S. 306 also finds that the existing patchwork of state and federal **laws** is perceived by the American public and the medical community to be confusing and inadequate to protect them from discrimination, and that federal legislation establishing uniform national standards is necessary to allow individuals to take advantage of genetic testing, technologies, research, and new therapies without concern for potential discrimination. *Id.*

[n239](#) *Id.*

[n240](#) See *id.* § 201(2)(B)(i) (referencing the Civil Rights Act of 1964, [42 U.S.C. § 2000\(e\)\(b\)\(2005\)](#)). Title VII of the Civil Rights Act of 1964 prohibits **employment** discrimination on the basis of sex, race, national origin, color, and religion. [42 U.S.C. § 2000\(e\)-2\(a\)](#). The ADA also covers employers with fifteen or more employees. [42 U.S.C. § 12111\(5\)](#) (2005).

[n241](#) See S. 306, *supra* note 20, § 201(2)(A)(i).

[n242](#) See *id.*, § 201(4).

[n243](#) *Id.*

[n244](#) *Id.* § 201(5). Genetic monitoring means:

The periodic examination of employees to evaluate acquired modifications to their genetic material, such as chromosomal damage or evidence of increased occurrence of mutations, that may have developed in the course of **employment** due to exposure to toxic substances in the workplace, in order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace.

Id.

[n245](#) Genetic services is defined as a genetic test, genetic counseling (such as obtaining, interpreting, or assessing genetic information), and genetic education. *Id.* § 201(6).

[n246](#) A genetic test "means the analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes," but does not mean an analysis of proteins or metabolites that "does not detect genotypes, mutations, or chromosomal changes." S. 306, *supra* note 20, § 201(7).

[n247](#) *Id.* § 202(a).

[n248](#) *Id.* § 202(b).

[n249](#) *Id.* § 202(b) (emphasis added).

[n250](#) *Id.* § 202(b)(5).

[n251](#) *Id.* § 202(b)(5). Written authorization from employees to conduct genetic monitoring is required to be obtained prior to the monitoring, and must be knowing and voluntary. S. 306, *supra* note 20, § 202 (6) (5).

[n252](#) *Id.*

[n253](#) *Id.*

[n254](#) *Id.* § 202(b)(5)(E).

[n255](#) *Id.*

[n256](#) *Id.* § 202(c).

[n257](#) S. 306, *supra* note 20, § 206 (providing rules for confidentiality of genetic information).

[n258](#) *Id.* § 206(a).

[n259](#) *Id.*

[n260](#) *Id.*; *cf. supra* note 197 (describing the ADA medical confidentiality rules, which in limited circumstances permit access to employee's medical records by supervisors, managers, and first aid and safety personnel).

[n261](#) S. 306, *supra* note 20, § 206(b).

[n262](#) *Id.* § 207(a) (providing the same remedies and procedures for violations of S. 306 as provided for violations of the Civil Rights Act of 1964).

[n263](#) *Id.*

[n264](#) [42 U.S.C. § 2000e](#) (2005); [42 U.S.C. § 1988](#) (2005); [42 U.S.C. § 1981\(a\)](#) (2005).

[n265](#) S. 306, *supra* note 20, § 208.

[n266](#) *Id.* § 207(f).

[n267](#) See Exhibit A for a summary of the workplace nondiscrimination and privacy protections related to genetic information that would be provided by S. 306.

[n268](#) See Elizabeth F. Defeis, *Equality and the European Union*, [32 GA. J. INT'L & COMP. L. 73 \(2004\)](#) (providing an overview of the EU approach to workplace equality).

[n269](#) *Id.* at 75.

[n270](#) See WPD 2004, *supra* note 11; see also The European Group on Ethics in Science and New Technologies, *Opinion: Ethical Aspects of Genetic Testing in the Workplace* (July 28, 2003), available at http://europa.eu.int/comm/european_group_ethics/docs/avis18EN.pdf [hereinafter EU Ethics Report].

[n271](#) See *supra* notes 140-44 and Part III.

[n272](#) EU Convention, *supra* note 140, art. 11.

[n273](#) *Id.* art. 12.

[n274](#) *Id.* art. 24, 25.

[n275](#) WPD 2004, *supra* note 11, at 2.

[n276](#) See, e.g., TREATY OF AMSTERDAM AMENDING THE TREATY ON EUROPEAN UNION, THE TREATIES ESTABLISHING THE EUROPEAN COMMUNITIES AND CERTAIN RELATED ACTS, Oct. 2, 1997, O.J. (C 340) 1 (1997) [hereinafter TREATY OF AMSTERDAM], incorporated into TREATY ESTABLISHING THE EUROPEAN COMMUNITY, Feb. 7, 1992, O.J. (C 224) 1 (1992). Article 13 of the Treaty of Amsterdam expanded protection from discrimination to categories beyond gender, notably race, ethnic origin, religion, disability, age, and sexual orientation. See Defeis, *supra* note 268, at 80.

[n277](#) See CHARTER OF FUNDAMENTAL RIGHTS OF THE EUROPEAN UNION art. 21, Dec. 7, 2000, O.J. (C 364) 1 (2000).

[n278](#) See EU Convention, *supra* note 140, art. 11.

[n279](#) See Kim, *supra* note 13, at 1500.

[n280](#) See *id.*

[n281](#) Equal Treatment in **Employment** Directive, Council Directive 2000/78/EC, 2000 O.J. (L 3003) [hereinafter Equal Treatment in **Employment** Directive]. The Treaty of Amsterdam is the source of authority for this Directive as well as for directives aimed at combating gender and race discrimination. TREATY OF AMSTERDAM, *supra* note 276; see Defeis, *supra* note 268, at 80-82.

[n282](#) Equal Treatment in **Employment** Directive, *supra* note 281, art. 1.

[n283](#) WPD 2004, *supra* note 11, at 5.

[n284](#) *Id.* What is particularly troubling in the context of genetic technologies is that they themselves have questionable predictive value. Because of this, the European Group on Ethics in Science and New Technology pointed out in its July 2003 opinion, "there is, up to now, no proven evidence that the existing genetic tests have relevance and reliability in the context of **employment**." See EU Ethics Report, *supra* note 270, opinion 2.9, at 15.

[n285](#) Equal Treatment in **Employment** Directive, *supra* note 281, art. 4. This same interpretation could be made of Member State legislation implementing the Directive.

[n286](#) See European Commission, *Genetic Testing: Patient's Rights, Insurance and Employment* -- A Survey of Regulations in the European Union 136 (2002), available at <http://www.univie.ac.at/zoologie/TheoretBio/Gentesting.pdf> (last visited Sept. 3, 2005) [hereinafter *EU Survey of Genetic Testing Regulation*] (citing the Disability Discrimination Act of 1995).

[n287](#) See *EU Survey of Genetic Testing Regulation*, *supra* note 286, at 136.

[n288](#) *Id.* at 137.

[n289](#) *Id.*

[n290](#) European Convention for the Protection of Human Rights and Fundamental Freedoms, *opened for signature* Nov. 4, 1950, art. 8, para. 1, 213 U.N.T.S. 222 (entered into force Sept. 3, 1953); CHARTER OF FUNDAMENTAL RIGHTS OF THE EUROPEAN UNION, *supra* note 277, art. 7.

[n291](#) See Privacy Directive, *supra* note 7, art. 2(a).

[n292](#) *Id.* art. 2(b) (emphasis added).

[n293](#) *Id.* art. 10.

[n294](#) *Id.* art. 6(1)(b).

[n295](#) See *id.* art. 7.

[n296](#) See *id.* art. 12.

[n297](#) Privacy Directive, *supra* note 7, art. 6(1)(c).

[n298](#) See European Commission, *National Data Protection Commissioners*, at http://europa.eu.int/comm/justice_home/fsj/privacy/nationalcomm/index_en.htm (last visited Sept. 3, 2005).

[n299](#) See *supra* notes 294-97 for a discussion of core privacy principles.

[n300](#) See Lasprogata et al, *supra* note 15, at P 34.

[n301](#) WPD 2004, *supra* note 11. The Article 29 Working Party is an advisory group composed of representatives of the data protection authorities of the Member States, which acts independently and has the task, inter alia, of examining any question covering the application of national measures adopted under the Privacy Directive in order to contribute

to the uniform application of such measures. See, e.g., Article 29 Data Protection Working Party, *Opinion on the Processing of Personal Data in the **Employment** Context* (Sept. 13, 2001), available at http://64.233.187.104/search?q=cache:0b0qrMyrL54J:europa.eu.int/comm./justice_home/fsj/privacy/docs/wpdocs/2001/wp48en_sum.pdf+Europa+working+party+opinion+on+the+processing+of+personal+data+in+the+employment+context+2001&hl=en.

[n302](#) See WPD 2004, *supra* note 11(citing the Privacy Directive art. 8).

[n303](#) *Id.* (citing the Privacy Directive art. 8(3)).

[n304](#) *Id.*

[n305](#) *Id.* at 6.

[n306](#) *Id.* at 10. This conclusion is well-supported by the findings and recommendation made by the European Group on Ethics in Science and New Technologies. See EU Ethics Report, *supra* note 270.

[n307](#) See Hendrickx, *supra* note 7, at 9; see also Article 29 Data Protection Working Party, *Opinion 8/2001 on the Processing of Personal Data in the **Employment** Context* Sept. 13, 2001, 5062/01/EN/Final, available at http://europa.eu.int/comm/justice_home/fsj/privacy/docs/wpdocs/2001/wp48en.pdf [hereinafter WPO].

[n308](#) For an extensive overview of the EU Privacy Directive's relevance to the **employment** context, see George et al., *supra* note 150.

[n309](#) See WPO, *supra* note 307, at 2. Although in practice the EU Privacy Directive directly affects human resources operations, within EU circles data privacy is not seen as a social/**employment** issue. This explains why human resources departments of U.S.-based multinationals were not ready for the Directive before 1998. See Angela R. Broughton et al., *International Legal Developments in Review: 1998 Business Regulations*, [33 INT'L LAW.](#) 291 (1999).

[n310](#) See WPO, *supra* note 307, at 19.

[n311](#) See *id.*

[n312](#) See George et al., *supra* note 150, at 755-59. The issue of "consent" raises many issues for employers. Many EU countries consider consent to be freely given only when the consent is not made a condition of **employment** and may be withdrawn at any time. See *id.* at 758. Some countries consider the consent to only be effective if agreed to by the employee's union or works council. See *id.* Additionally, if consent is given at the outset of the **employment** relationship, it may not be broad enough to cover subsequent data collection, or if the same data is used for multiple purposes, it may be necessary to obtain consent for each use. See *id.*

[n313](#) See *id.* at 755.

[n314](#) See, e.g., Data Protection Act, 1998 (Eng.), available at http://www.hms.gov.uk/acts/acts_1998/19980029.htm#aofs (last visited Sept. 3, 2005).

[n315](#) See *supra* note 71 and accompanying text for a discussion of the ways genetic information may be acquired by employers.

[n316](#) Privacy Directive, *supra* note 7, art. 8. All member states have implemented the idea of a general ban on processing sensitive data with variations of the above two noted exceptions. See Hendrickx, *supra* note 7, at 36.

[n317](#) See WPD 2004, *supra* note 11 (emphasis added).

[n318](#) See Privacy Directive, *supra* note 7, art. 8(2)(a), 8(3). The ban on processing of sensitive data is also lifted where the "processing is necessary for the purposes of carrying out the obligations and specific rights of the controller in the field of **employment law** in so far as it is authorized by national **law** providing for adequate safeguards." *Id.* art. 8.2(b). This may be a relevant exception where, for instance, the employer has a designated religious affiliation that is important to the **employment** relationship. For example, it may be acceptable under national **law** for a Catholic elementary school to ask a prospective teacher his or her attitudes toward the Catholic religion. Hendrickx, *supra* note 7, at 42. This exception may potentially have broad application, but is entirely dependent on the extent to which Member States define employer obligations in their national **employment** and labor **laws**. WPO, *supra* note 307, at 17.

[n319](#) Privacy Directive, *supra* note 7, art. 8(2)(a).

[n320](#) See MARK FREEDMAN, DATA PROTECTION AND **EMPLOYMENT** IN THE EUROPEAN UNION: AN ANALYTICAL STUDY OF THE **LAW** AND PRACTICE OF DATA PROTECTION AND THE **EMPLOYMENT** RELATIONSHIP IN THE EU AND ITS MEMBER STATES 32-33 (1999) (discussing the difficulty in using consent as a hard-edged principle in the **employment** context where privacy issues are at stake).

[n321](#) The United States considers control of employee privacy a "managerial prerogative in a non-union workplace" and equates "knowledge of an employer's [privacy] policy with consent to be bound to it." See Matthew Finkin, Book Review, [21 COMP. LAB. L. & POL'Y J. 813, 814 \(2000\)](#) (reviewing JOHN D.R. CRAIG, PRIVACY & **EMPLOYMENT LAW** (1999)).

[n322](#) See WPO, *supra* note 307, at 3.

[n323](#) See *id.* at 23.

[n324](#) See Hendrickx, *supra* note 7, at 36.

[n325](#) *Id.* at 38 (citing the Data Protection Act of 1998, art. 7 (Port.)).

[n326](#) Privacy Directive, *supra* note 7, art. 8(3).

[n327](#) Hendrickx, *supra* note 7, at 45.

[n328](#) *Id.* at 47.

[n329](#) *Id.*

[n330](#) *Id.* at 47-48.

[n331](#) *Id.* at 48.

[n332](#) *Id.* at 48-49.

[n333](#) Hendrickx, *supra* note 7, at 62.

[n334](#) See *EU Survey of Genetic Testing Regulation*, *supra* note 286 (citing The Gene Technology Act, Gentechnikgesetz, BGB1. Nr. 510/1994).

[n335](#) See Hendrickx, *supra* note 7, at 48.

[n336](#) *EU Survey of Genetic Testing Regulation*, *supra* note 286, at 44 (citing The Act on the Protection of Privacy in Working Life, No. 477, October 1, 2001).

[n337](#) *Id.*

[n338](#) *Id.*

[n339](#) *Id.* For example, Denmark refers to health-related data in its legislation implementing the Privacy Directive, but does not specifically mention genetic data. Denmark also has legislation, Act No. 286 of April 24, 1996, on the Use of Health Information in the Labor Market, which decreases the potential for employers to ask potential employees for health-related information. See *id.* at 34.

[n340](#) Germany does not legislate genetic testing; however, the German Bundestag Commission of Inquiry has recommended that employers should not be allowed to ask for the results of genetic tests as a prerequisite for **employment**. See *EU Survey of Genetic Testing Regulation*, *supra* note 286, at 62. Greece provides another example: This country addresses the privacy of medical examinations and health data in Article 371 of its Penal Code which forbids the processing of such personal data except where authorized by the data subject's written consent. *Id.* at 67. The United Kingdom has addressed the topic in its Code of Practice interpreting the Data Protection Act of 1998. The Information Commissioner issued the Code as guidance to data controllers in interpreting the Data Protection Act. Employers have a vested interest in the Code as it addresses the **employment** relationship and data protection issues in general. "With respect to genetic testing or data, the United Kingdom broadly takes the view that genetic testing might, in exceptional circumstances, be valid on health and safety grounds, but advances will be needed before it can safely be used to make decisions based on predictions of possible future ill health." *Id.* at 136. See also GeneWatch, *Genetic Testing in the Workplace* (2003), available at <http://www.genewatch.org/HumanGen/publications/Reports/GeneticTesting.pdf>.

[n341](#) See *supra* notes 234-69 and accompanying text. Because H.R. 1227 that is currently pending in the House of Representatives is essentially identical to S. 306, no separate analysis of its strengths and weaknesses is necessary at this point. See *id.*

[n342](#) See Exhibit A, providing a comparison of U.S. and EU genetic privacy and nondiscrimination protections for private-sector workplaces.

[n343](#) See *supra* notes 320, 327 and accompanying text.

[n344](#) See *supra* notes 303-08 and accompanying text.

[n345](#) See, e.g., Kim, *supra* note 13, at 1500-01.

[n346](#) See *id.*

[n347](#) See *supra* notes 73-77 and accompanying text. See also Peter J. Hustinx, *European Data Protection Supervisor (EDPS), The Role of the European Data Protection Supervisor in the EU Framework for Data Protection, Remarks Before the Polish Parliament*, available at http://www.edps.eu.int/publications/speeches/04-05-26_Warsaw_speech_en.pdf. Hustinx discusses the difference between protection of "privacy" that relates to the fundamental right that everyone has to respect for his or her private and family life, home, and communications and protection of "personal data" concerning him or her, commenting that data protection is wider than privacy protection, because it also relates to other fundamental rights and freedoms of individuals. But at the same time data protection is more specific, because it only deals with the processing of personal data. *Id.*

[n348](#) See *supra* notes 199-206 and accompanying text.

[n349](#) See *supra* notes 240-41 and accompanying text.

[n350](#) See *supra* notes 150-62 and accompanying text.

[n351](#) See Exhibit A, providing a comparison of U.S. and EU genetic privacy and nondiscrimination protections for private-sector workplaces.

[n352](#) See *supra* notes 233-67 and accompanying text.

[n353](#) See Lasprogata et al., *supra* note 15, at PP 41-49.

[n354](#) See *id.*

[n355](#) See *supra* notes 248-49.

[n356](#) See *id.*

[n357](#) See Lasprogata et al., *supra* note 15, at PP 41 -- 49.

[n358](#) See *id.*

[n359](#) See *supra* note 252 and accompanying text.

[n360](#) Some states have **laws** that give employees the right to review the contents of their personnel files, including medical files. See, e.g., [ORE. REV. STAT. § 652.750](#) (2005) (providing a statutory right for employees to inspect their personnel records).

[n361](#) See Lasprogata et al., *supra* note 15, at PP 41-49.

[n362](#) See *id.* P 45.

[n363](#) See *id.*

[n364](#) See *id.* PP 41-49.

[n365](#) See *id.*

[n366](#) See *id.* PP 41-49.

[n367](#) See WPD 2004, *supra* note 11, at 10.

[n368](#) See, e.g., Kim, *supra* note 13, at 1500-01.

[n369](#) See *id.*

[n370](#) See Exhibit A, providing a comparison of U.S. and EU genetic privacy and nondiscrimination protections for private sector workplaces.

[n371](#) See *id.*

[n372](#) See *id.*

[n373](#) See *supra* note 223 and accompanying text.

[n374](#) See Exhibit A.