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Final Paper

### Genetic Discrimination Post-GINA

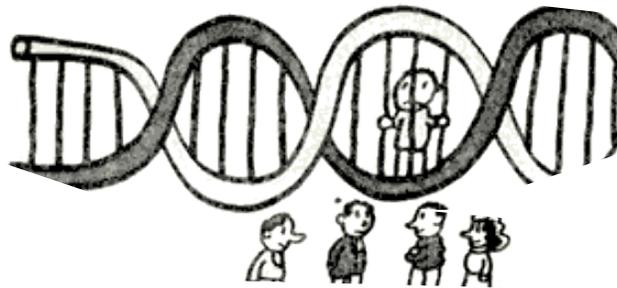
Vincent Freeman was conceived naturally. Without the benefit gene selection technology, he has a litany of health risks that preclude him from many of society's jobs. In essence, he faces genetic discrimination. The world created by the film *Gattaca* is not hard to imagine: with the completion of the Human Genome Project and advance of personal genomics, the risk of developing certain diseases can be deduced from an individual's genome. Fortunately, the Genetic Information Non-Discrimination Act took significant strides against genetic discrimination. Yet the struggle for genetic civil liberties continues post-GINA, with a lack of information on both patient and physicians parts hampering genetic testing efforts and limiting the effectiveness of genomics research; to gather the benefits from genetic testing, education about genetic discrimination law is necessary.

### **History of Genetic Discrimination**

Concerns about genetic discrimination arose in the 1990s. The Ethical, Legal and Social Implications Working Group of the Human Genome issued a report that presented the possibilities of genetic discrimination in insurance and employment, recommending that they be eligible for insurance regardless of knowledge about potential diseases. The Health Insurance Portability and Accountability Act, passed in 1996 became the first federal law that provided protection against genetic discrimination in health insurance. It prevented health insurers from excluding people from group coverage based upon past medical problems, which included

genetic predisposition to diseases. However, it only applied to “employer-based and commercially issued group health insurance” (“Genetics Privacy”, 2008).

The push for more comprehensive genetic discrimination began in 1995 when Representative Louise Slaughter introduced genetic



nondiscrimination legislation to Congress for the first time. In 1997, the movement gained more traction when various organizations formed the Coalition for Genetic Fairness, which aimed to educate the public about genetic discrimination. The Genetic Information Non-Discrimination Act was first introduced in 2002, and faced opposition in both the House and Senate over the years, each time the margin of passing it becoming smaller. Finally, in the 110th Congress, GINA was passed through the House on April 25, 2007. The Senate passed the bill a year later, on April 24, 2008, and it was signed into law by Bush on May 21, 2008.

GINA protects against “discrimination on the basis of genetic information,” which is defined as “information about such individuals’ genetic tests, the genetic tests of family members of such individual, and the manifestation of a disease or disorder in family members of such individuals” (110th Congress). GINA is divided into two separate titles: Title I addresses genetic nondiscrimination in health insurance. GINA prevents insurance companies from using genetic information diseases to reduce coverage or increase costs for asymptomatic individuals. It also prohibits insurance companies from requiring individuals to provide genetic information or undergo genetic testing. Title II address genetic nondiscrimination in employment, prohibiting employers from using genetic information in making decisions for hiring or any other job-related decisions. Like insurance companies, employers may not require genetic information from an individual or his family, except when it is inadvertently provided by the individual’s medical

history, when it is publicly available, or when it is part of an employee-sponsored monitoring of employee health program. In these cases, employers can only access the collective group's genetic information, rather than individuals'.

However, GINA does have some gaps. It does not cover genetic discrimination for life, disability and long-term insurance, does not apply to employers with fewer than fifteen employees, and does not include symptomatic individuals. This means that people may have fear of genetic discrimination due to other types of insurance. Additionally, because GINA only applies to asymptomatic individuals, insurance companies may drop coverage for someone who begins to develop symptoms. The Affordable Health Care Act, which will come into effect in 2014, addresses this issue. The Affordable Health Care Act prevents insurance companies from discriminating against individuals on the basis of health status, with genetic information listed as a factor in health status. It also prohibits insurance companies from dropping the coverage of individuals once symptoms manifest (Walker, 2012). Gaps have also been filled by state legislation, including California's Genetic Information Non-Discrimination Act, which extends non-discrimination law in housing, mortgage lending, employment, education, and public accommodations to genetic discrimination (Pico, 2011).

### **Post-GINA**

While efforts are slowly attempting to address the gaps in genetic discrimination not covered by GINA, lack of a well-known, comprehensive genetic nondiscrimination law hinders scientific advancement in personal genomics.

Genetic testing is important because first, it increases the likelihood that researchers can discover therapy for diseases that have a genetic component. More information about individuals with a disease or a family history of disease allows researchers to identify potential areas and

SNPs in the genome that are related to the disease, and subsequently test an array of genome-based therapy, with anything from gene therapy to rational drug design. Second, genetic testing can be beneficial to the individual being tested, because having knowledge about genetic predisposition to a certain disease may help doctors detect problems early on, enhancing the chance that preventive treatment will be employed or the disease is caught in its developmental stages (“Genetic Privacy”, 2008).

Despite the clear benefits of being tested for hereditary diseases and legislation guarding against genetic discrimination, there is still widespread reluctance to be tested. As the National Human Genome Research Institute explains:

Public fears about genetic discrimination mean that many individuals do not participate in important biomedical research at the NIH. Many patients also refuse genetic diagnostic tests that help doctors identify and treat diseases: they worry that they will lose their health insurance if it is proven that they are genetically pre-disposed to a disease” (“Genetic Discrimination”, 2012).

This fear is particularly prevalent in Huntington’s Disease, in which having the gene means an inevitable onset of the gene in middle age. Bombard et. al (2012) found that 86 percent of the respondents in their study were concerned about genetic discrimination to themselves or their family members at a point in their lifetime. Because of this fear, individuals forego therapeutic or management opportunities to individuals with Huntington’s disease, and healthcare providers are incapable of helping their patients to their fullest extent (Bombard et.al., 2012). Specific strategies of patients at risk for Huntington’s disease involved avoiding applying for insurance and keeping information about Huntington’s disease out of their medical file.

Setting/Item <sup>a</sup>	
Overall	
Insurance	Patients also reported
By a life insurance company or agent	
By a long-term disability company or agent	subtler forms of
By a mortgage company or agent	
Family	discrimination, from being
When making choices about having children	
By your spouse	“cautious” because of the fear
By a member of your family	
Social	of genetic discrimination, to
When establishing a relationship	
By your community	perceiving employers as
By a boy/girlfriend	
By a friend	giving fewer projects and
At school	
By your religious organization	other work-related
Employment	
At work	opportunities to those with
When getting hired or getting a job	
Health care	genetic predispositions or
When getting medical care	

diseases. As Klitzman (2010) writes, “Subtle forms of discrimination could exist that may make it too early for patients to risk discrimination by disclosing fully and widely...Caution and discretion remain key.”

These subtle types of discrimination highlight another flaw of GINA—its enforceability. Investigation by the Equal Employment Opportunity Commission (EEOC), the agency charged with inspecting employment practices and instances of genetic discrimination, is limited, as highlighted in the court case *EEOC v. Nestle*, a U.S. district court case. The judge in the case explained, “while the Court recognizes that it is important for the EEOC to have the ability to investigate possible patterns of discriminatory action, this does not mean that every charge of discrimination justifies an investigation of the employer’s facility-wide employment practices” (Wagner and Vorhaus, 2012). Because in many cases, discrimination is not overt and may be from the perceived culmination of various factors, it is difficult to translate de jure nondiscrimination into de facto equality of opportunity.

An information gap on both the physicians and the patients' part seems to fuel continued genetic discrimination. Klitzman's (2010) study interviewed a sample of people who were at risk for highly hereditary diseases, and the results

“Suggest that wide and profound confusion about health insurance exists—e.g., what insurance companies are required to offer. Misunderstandings and confusion regarding the law (e.g., the transferability of insurance), exacerbated by mistrust of insurance companies' motives, can lead to fears of possible discrimination that may or may not be entirely realistic, but nonetheless prevail.”

Despite GINA providing a baseline for nondiscrimination, then, will be less effective without the proper avenues of information dissemination. This lack of information is not simply a patient-based phenomenon. A study by Huizenga (2009) of California Medical Association and other California medical organization members found that 75 percent believed fear of genetic discrimination would cause patients to decline testing. More importantly, more than 60 percent were not aware of laws, both federal and California, prohibiting health insurance discrimination. Finally, 11 percent chose concern of genetic discrimination as a reason for nonreferral. Physicians thus feed into the problem of lack of genetic testing by not referring patients to receive a genetic test. Currently, fear of genetic discrimination fueled by lack of information hampers the full potential of GINA and other genetic nondiscrimination legislation. An information gap also exists between geneticists and non-geneticists. A study conducted by Huizenga et. al. (2010) demonstrated that the mean knowledge score of cancer geneticist professionals was significantly higher ( $p < 0.001$ ) than that of non-geneticists.

## **A Path Forward**

HIPAA, GINA and the Affordable Care Act mark important steps toward diminishing the level of genetic discrimination faced by individuals. As genomics has the increasing capacity to advance medicine and treatment, the coverage gaps that plague these pieces of legislation, such as lack of protection from genetic discrimination in disability, life and long-term insurance, must be patched. States should follow the lead of states like California. Currently, one third of states have either no policy on genetic discrimination, or only address either genetic discrimination in employment or health insurance (“Genetic”). More comprehensive genetic discrimination legislation at the state level can help cover cracks in federal legislation. Second, education about genetic testing should be promulgated. This should start with physicians, as they are trusted by patients, and often are in the position to make referrals during a patient’s treatment. Only with proper information and education can individuals make decisions based not upon fear, but genuine effort to preserve their own well-being.

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