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## Imperfect Remedies: Legislative Efforts to Prevent Genetic Discrimination

*Timothy J. Aspinwall\**



The challenge of providing fair access to affordable health care is a perennial political issue in the United States. One component of the ongoing debate is how to define and implement the appropriate uses of medical advances. Genetic medicine is one area that most agree holds great promise to provide cost-effective care. The huge potential of genetic medicine has, however, been impeded by genetic discrimination. The effort to prevent genetic discrimination has resulted in two recent pieces of federal legislation—one has become law, and one is pending as part of the larger health care reform bill.

The Genetic Information Nondiscrimination Act of 2008 (GINA) was signed into law by George W. Bush in May 2008, after having passed through both houses of Congress with broad bipartisan support.<sup>1</sup> GINA helps to ensure affordable access by providing significant protections against genetic discrimination in health care and employment. The protections afforded by GINA could be largely subsumed by the protections that would be provided in the health care reform legislation pending in Congress. For purposes of this discussion a review of the pending legislation will include only the Patient Protection and Affordable Care Act (PPAC) recently passed in the U.S. Senate.<sup>2</sup>

As compared to PPAC, GINA provides incomplete protection in that it allows some forms of continued genetic discrimination. Both pieces of legislation are imperfect largely because protections against genetic discrimination result in forced transfers of wealth between private parties in ways that are not explicit in either piece of legislation, nor acknowledged in the Congressional findings. These limitations, however, do not detract from the importance of the imperative to end genetic discrimination.

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1. Pub. L. No. 110-233 § 102(b)(1)(B) 122 Stat. 881 (2008).  
2. H.R. 3590, 111<sup>th</sup> Cong. (2009).

The history of genetic discrimination in the United States is shameful. The Congressional findings accompanying GINA offer a small glimpse of our problematic history of genetic discrimination.<sup>3</sup> Beginning with the first sterilization law enacted by the State of Indiana in 1907, and then followed by similar statutes in a majority of states by 1981, the laws were a misguided effort to eliminate supposedly undesirable genetic traits.<sup>4</sup> The Congressional findings point out that genetic discrimination has frequently impacted ethnic minorities.<sup>5</sup> In the early 1970's the proliferation of state laws requiring mandatory screening of all African Americans for sickle cell anemia contributed to employment discrimination against African Americans. An example, although not referenced in the Congressional findings, is that both the U.S. Air Force and major commercial airlines previously excluded sickle cell carriers from service as pilots on the false premise that carriers are subject to high altitude sickle cell anemia attacks. To help prevent specific types of discrimination, Congress in 1972 passed the National Sickle Cell Anemia Control Act, which, among other things, withholds monies from states that have compulsory sickle cell testing.<sup>6</sup> The Congressional findings also point out more recent instances of genetic discrimination in the workplace exemplified by the use of pre-employment genetic testing.<sup>7</sup>

In enacting GINA, Congress found that it has a “compelling public interest in relieving the fear of discrimination and in prohibiting its actual practice in employment and health insurance.”<sup>8</sup> In so finding, Congress noted that “. . . [w]hile many states have enacted some type of genetic non-discrimination law, these laws vary widely with respect to their approach, application, and level of protection. . . . [t]he American public and the medical community find the existing patchwork of State and Federal laws to be confusing and inadequate to protect them from discrimination.”<sup>9</sup> GINA is intended to establish a basic uniform standard of protection against discrimination.

GINA provides the following protections. First, health insurers in the individual and group markets are prohibited from basing eligibility decisions or rate setting on genetic information. Second, employers with fifteen or more employees are prohibited from basing hiring, firing, or

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3. Pub. L. No. 110-233 § 2.

4. See 1907 Ind. Acts page no. 377, available at <https://scholarworks.iupui.edu/handle/1805/1053>.

5. Pub. L. No. 110-233 § 2.

6. Pub. L. No. 92-294, 86 Stat. 138 (1972).

7. See *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1269 (9th Cir. 1988) (favoring employees' rights to genetic privacy).

8. Pub. L. No. 110-233 § 2(4).

9. *Id.* § 2(5).

promotional decisions on genetic information. For purposes of this statute, genetic information is defined as: (i) individual genetic tests; (ii) genetic tests of family members of such individuals; and (iii) the manifestation of a disease or disorder in family members of such individual.<sup>10</sup>

Although GINA provides significant protections against genetic discrimination, there are notable gaps in coverage. First, GINA does not prohibit health insurers in either the individual or group markets from basing rate-setting decisions on the manifestation of a disease or disorder. It is an unfortunate irony that insurers are free to increase rates precisely at the point when individuals most need affordable coverage—when a genetic disorder becomes manifest. Second, GINA does not protect against the use of genetic information in the context of long-term care insurance, disability insurance, or life insurance. As a consequence of these broad exceptions to the protections afforded by GINA, individuals still have much at risk in deciding whether to undergo potentially beneficial genetic testing and treatment. To the extent that an individual may wish to obtain long term care insurance, disability insurance, or life insurance, and to the extent that the premium levels or availability of coverage are based on genetic information, individuals might quite reasonably decide to forgo potentially beneficial genetic testing rather than obtain information that could exclude them from the coverage they may need or result in cost prohibitive premiums.

The ongoing possibility of genetic discrimination creates disincentives for individuals to undergo potentially beneficial testing and treatment. This makes it less likely that patients, clinicians, and researchers will benefit from the full potential of genetic medicine. The fact that certain forms of genetic discrimination are not prohibited is a partial defeat of Congress' stated objective of relieving the fear of genetic discrimination.

PPAC would provide greater protections from genetic discrimination in health care insurance in that it would: (i) strictly limit the actuarial bases upon which premium levels are set to criteria such as rating areas, an individual's age, and tobacco use; (ii) guarantee the issuance and renewability of coverage; and (iii) prohibit discrimination against individuals based upon criteria including health status, medical condition, medical history, genetic information, or disability.<sup>11</sup> These protections are quite comprehensive, but not without controversy.

As with almost all health care legislation, GINA and PPAC represent an uneasy balance between competing interests. It is clear that GINA provides only partial protection against genetic discrimination. Is this a fair and reasonable status quo, or is it simply one more step toward more complete

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10. *Id.* § 201(4)(a).

11. H.R. 3590, 111<sup>th</sup> Cong. (2009).

protections? Should individuals be entitled to the greater protection against genetic discrimination as provided by PPAC, or should insurers have more freedom to base underwriting decisions upon all relevant information—including genetic information?

The purpose of health care insurance is to allow individuals to obtain health care at a predictable and affordable cost. Insurers also seek predictability by setting premium levels based on actuarial data. Indeed, insurers are generally prohibited from charging different premiums for different groups or individuals without actuarial justification. This requirement of actuarial equity helps ensure the solvency of insurance carriers and prevents unfair discrimination in pricing. These are settled principles of insurance underwriting and are included in the Model Laws by the National Association of Insurance Commissioners. In this light, it is quite reasonable and actuarially equitable for insurance carriers to take into account genetic information in setting insurance premiums.

This requirement of actuarial equity, however, is a challenge to the social objective of maximizing the benefits of genetic medicine and more specifically, the congressional intent of removing genetic discrimination. In this respect, Congress has essentially said that the social interest in preventing genetic discrimination in health care far outweighs the principle of actuarial equity.

This argument, based on principles of moral equity, has substantial appeal. The essential point is that actuarial equity fails to take into account the moral inequity of increasing premiums on persons who suffer from genetic conditions through no fault of their own. This moral argument, however, must contend with another dilemma, which is that the prohibitions against accessing and using genetic information will create an imbalance of information where the insured has more information than the insurance carrier. The problem is that the imbalance of the information creates opportunities for individuals to game the system. For example, any person who discovers that he or she has a genetic susceptibility to a potentially devastating disease will be incentivized to purchase more comprehensive health care insurance than they otherwise would—at a price that does not reflect the actuarial risk.

The fact that a person can obtain health care insurance at an affordable price is a laudable outcome. The mechanism by which this is achieved is not so uncontroversial. The practical effect of the prohibitions against genetic discrimination is that insurance carriers will have medical losses that they cannot predict based upon individual data. Insurers will be forced to aggregate their losses, which will be reflected in increased premiums for all policyholders rather than for those who present the increased risk.

In a very real way, GINA and PPAC result in a transfer of wealth between private parties by government fiat. There is simply no way to

avoid the fact that prohibitions against genetic discrimination will require that those who do not have genetic conditions will subsidize the cost of coverage for those who do. That Congress has chosen to impose this cross-subsidy represents a choice that it is better for society to spread the risk rather than allow individuals with genetic conditions to suffer the double misfortune of not having affordable health care. In a more perfect system, however, these transfers of wealth would be more transparent and would not require one group—in this instance, private insurance policyholders—to bear the burden of socially desirable health care reform.

The imperative to eliminate genetic discrimination enjoys broad-based support. Perhaps as a practical matter, GINA and the pending provisions in PPAC represent the best possible remedy to the problem of genetic discrimination. This seems especially true given that one of the most frequently cited alternatives to further insurance regulation is to provide wider access to government health care programs. Such efforts have proven to be politically challenging, to say the least.

Importantly, however, there is a general recognition that the full benefits of genetic medicine can only be realized if people are protected from discrimination that may accompany genetic testing and treatment. For this purpose, GINA is an advance from the previous status quo. To the extent that individuals remain subject to genetic discrimination in health care, the Congressional objectives of GINA have not been fully met. Perhaps pending legislation will provide a more complete, albeit imperfect, remedy.