

# Genetic nondiscrimination

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**The identification and investigation of sentinel cases has illuminated genetic discrimination in the US. Its occurrence impedes applications of biotechnology and is a primary focus of public policy activity at the federal level. Continued research and informed responses may make genetic nondiscrimination more likely.**

More than a decade ago, my collaborators and I began a scientific assessment of genetic discrimination in the US<sup>1</sup>. This work spurred numerous studies and a lively professional discussion about the exact nature of genetic discrimination and its import and frequency in society<sup>2</sup>.

An initial critique of our findings focused on the definition of this form of discrimination. It was argued that the first published cases did not constitute genetic discrimination, because genetic discrimination must arise solely from effects or perceptions directed by the genome, and that the reported cases were really a form of disability discrimination that was well known in US society and jurisprudence<sup>3</sup>. On closer examination, however, the coercion in prenatal testing settings of parents who were carriers of cystic fibrosis and the inability of asymptomatic homozygotes with respect to mutations at the hemochromatosis locus on chromosome 6, who were undergoing regular effective preventive phlebotomies, to purchase insurance countered this argument. The report of a family with long QT syndrome whose asymptomatic affected children could not qualify for insurance coverage for their care, including the preventive drug treatment, effectively silenced this criticism<sup>4</sup>.

Two other arguments persisted. The first held that the evidence for cases of genetic discrimination was anecdotal and that such cases were fleetingly rare if they occurred at all. The initial data supporting the occurrence

of genetic discrimination were based on key cases and incomplete methods of data collection. But critics did not acknowledge that a study accurately measuring the incidence or prevalence of this phenomenon would possibly require victims of discrimination to endure more adverse events as a result of their participation. It would also require the cooperation of the institutions and businesses that were the agents of this form of discrimination. Evocations of business secrecy about their processes and of potential legal liability as a result of their participation effectively inhibited research that might have illuminated this issue. Up to this moment, no one knows how many people have suffered or are suffering unfavorable consequences of decisions based on their genetic information.

The second argument centered on a 'right to discriminate.' Certain social processes are discriminatory: selection for a job, admission to a school, offering of various contracts. The ability of the businesses and institutions that participate in these events to operate appropriately, it was argued, depends on the availability of the best possible information, including, if they are deemed valuable, individual genetic tests or their results. Not only must such institutions be able to discriminate on this or other bases, but they also must have access to such personal information. This argument has never been completely refuted, a sign of its strength, but polls and subsequent public policy determinations suggest that limitations of these business-based prerogatives are publicly acceptable and desirable.

Despite these and other questions surrounding genetic discrimination and ongoing research on the topic, the National Center for Human Genome Research made this issue an early and important part of its policy activity at the national level<sup>4,5</sup>. But it was "the laboratory

of the States" where policy development and implementation initially occurred. Beginning in the early 1990s, bellwether states such as California began passing legislation prohibiting genetic discrimination in health insurance practices and employment settings<sup>6</sup>. Most states now have laws prohibiting adverse use of predictive genetic information in insurance and employment practices. Variation in language, coverage and effectiveness of state laws is part of the impetus to pass basic federal legislation enforcing genetic nondiscrimination.

Early strong opposition and lobbying by the insurance industry and chambers of commerce against legislation prohibiting genetic discrimination at the state level was evident. It was offset somewhat by the recognition by some members of the life-science and health-care industries that fear of discrimination might curtail interest in new tests and associated treatments or the proper use of genetic information in medicine. Genetic discrimination might hinder the development of new markets that are sensitive to consumers' experiences and perceptions. Informing individuals with genetic diseases or research subjects of the risk of discrimination before they undergo testing has since become standard practice for clinical and research professionals. In the late 1990s, investment prospectuses for biotechnology companies began warning potential investors that discrimination or fears of it might adversely affect the business outlook for these enterprises. Recent statements by John Rowe, CEO of insurance giant Aetna Inc., establishing nondiscriminatory policies for his company suggest that key businesses may have mollified their hostility to curbs of discriminatory practices<sup>7</sup>. Laboratory Corporation of America Holdings (LabCorp), one of the largest providers of genetic testing services in the US, has acknowledged the potential for

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adverse discrimination and called for appropriate policies to protect individuals against it. LabCorp was a cosignatory of a letter supporting genetic nondiscrimination legislation in the US House of Representatives posted by the Genetic Alliance in 2005.

The impact of sentinel cases continued. *Norman-Bloodsaw versus the Regents of the University of California and the Lawrence Berkeley Laboratories*, and the later court and Equal Employment Opportunity Commission's actions arising from events at the Burlington Northern Railroad Company, highlighted the role of genetic discrimination in employment practices<sup>8,9</sup>. But it was not until cases came to light of federal employees who had developed genetically-based conditions after many years on the job and were being denied earned benefits because these conditions were deemed 'pre-existing' at the time of their initial employment (such policies seemed to be legal under extant federal policies) that the Executive Branch of the US government took action.

These and other discriminatory practices in federal employment were banned by then-President Clinton in 2000 (Executive Order 13145, 8 February 2000). After several attempts, the US Senate passed a federal genetic nondiscrimination bill last year, but it was not taken up by the House (S. 1053 passed unanimously in the US Senate on 14 October 2003). This year, the Senate has again unani-

mously sent a bill to its partner legislative body. A broad range of business, professional, community and other parties endorse its passage and enactment, recognizing that elimination of genetic discrimination and fears associated with it may facilitate the appropriate development and deployment of genetically based human biotechnologies. Enacting this legislation this year would be a crucial milestone.

But the specter of genetic discrimination extends further than insurance or employment abuses. I was recently asked to consult on a case in which a woman had allegedly been repeatedly assaulted by her husband. She petitioned a court to end her marriage and grant her custody of her two young children. Her husband countered in a legal filing that she had a family history of Huntington disease, that this disorder underlay her complaints and rendered her claims for child custody inappropriate. After clinical evaluations at respected health institutions did not confirm any medical evidence of Huntington disease, the husband sought judicially ordered, forced genetic testing for the DNA expansions linked to the disorder. Nonconsensual, compulsory genetic testing carries the risks of genetic discrimination and can confuse the import of phenotypic effects and genotypic risks in civil and criminal evaluations.

Scientific funding, investigation and the involvement of informed scientists in the discussion of genetic discrimination have been

fruitful. The importance of case-based investigation in uncovering problems, and providing compelling stories that are vital to the media depiction of the issue and the public policy process, has been amply demonstrated and should not be underestimated in the future. Finding and investigating cases is an important part of science's contribution to society. But the translation of developments in biomedical research to practical and useful technologies that benefit society and do not unnecessarily harm individuals is a continuous challenge for scientists and those who seek applications of science. Genetic discrimination will require further study and more vigilance in order to truly optimize conditions for risk assessment and predictive medicine.

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7. Testimony of John W. Rowe, M.D., Chairman and CEO, Aetna Inc. before the House Judiciary Subcommittee on the Constitution. 12 September 2002.
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