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After Long Gestation and Difficult Labor, GINA Is Born

Editor's Note: Please also see a [related story](#) on GINA on the Alzheimer Research Forum.

24 June 2008. In May, President George W. Bush signed into law the Genetic Information Nondiscrimination Act, informally known as GINA. The legislation had overwhelming support in the 110th Congress, having passed the Senate unanimously and the House of Representatives in a vote of 414-1. Although the target of the act is genetic discrimination by insurers and employers, some researchers believe there may be a secondary benefit for the scientific enterprise.

The new law prohibits group and individual health insurers from requesting or purchasing family health history or genetic test results of any individual or family members—defined as first- through fourth-degree relatives—and bars insurers from using this information to determine an individual's eligibility for coverage or to set premiums. Employers are also banned from using such information in hiring, firing, job assignments, or compensation decisions.

Though GINA enjoyed strong congressional backing in this session, the legislation has taken a lengthy and circuitous path to the president's desk. First introduced by Rep. Louise M. Slaughter (D-NY) in 1995, the bill has seen many modifications and slowly gathered steam over the years as both genetic testing and the concept of personalized medicine became mainstream. House member Judy Biggert (R-IL) became a supporter, while on the Senate side, Edward M. Kennedy (D-MA), Olympia M. Snowe (R-ME), and Mike Enzi (R-WY) were early champions of GINA.

"It has been an enormously lengthy battle to win its adoption," says Paul Appelbaum, an expert on psychiatry and law at Columbia University.

Joann A. Boughman, CEO of the American Society of Human Genetics (ASHG), credits Health and Human Services Secretary Mike Leavitt with bringing the Bush Administration on board for GINA. As a former governor of Utah, Leavitt has a strong interest in genealogy and genetics, and he has become a leading advocate of personalized medicine based on genetic information. Boughman cautions, however, that GINA provides no protections in the areas of life insurance, disability insurance, or long-term care insurance.

Changing perceptions

Though GINA has little direct impact on the research enterprise, Boughman and others believe that the law will increase participation in genomic studies by lessening subjects' fears about possible future implications of genetic testing.

"The way we see this bill helping research is not actually in the letter of the law but in the intent of the law," says Boughman. "Most genetics studies anonymize samples or family histories, but somewhere in the phenotype-genotype correlations, there is identifying information. People have had the fear that if they participated in research, that information could get out, and if it got out it could be misused. What GINA does is prevent at least that last step, so hopefully people will not be as encumbered by this fear when having genetic tests in their clinical care or in research. So we do believe it will enhance

participation in research.”

Applebaum agrees. “To a considerable extent, the research enterprise has been insulated from the negative effects of the system as it existed prior to the passage of this legislation, so my guess is that the largest impact for research will result from a change in the perceptions of potential research subjects in regard to the risk they run by having genetic testing performed in general,” Appelbaum says. “Few ordinary people are aware of the complexities of HIPAA [the Health Information Portability and Accountability Act] or GINA. They’re simply aware that there’s a risk that if you have genetic testing performed it may someday be used against you. Now, with the passage of GINA, I think that perception is likely to diminish, and that would be a good thing.”

Despite the fact that GINA's impact is primarily in the health care and employment realms, Boughman predicts that the Institutional Review Boards (IRBs) that regulate and monitor research involving human subjects will be heartened by the additional protections provided by GINA, a view shared by Irving Gottesman, emeritus professor of psychology at the University of Minnesota and a pioneer in genetic studies of schizophrenia.

“It’s tough enough to get things done in this area, worrying about the future and making promises that what we’re doing, SNP-by-SNP, will aggregate and will tell us something in the future. [The passage of GINA] makes it easier to get by the IRBs, who are overly concerned about some things that we believe should be left to our discretion as researchers,” Gottesman says. “The IRBs are doing their jobs as best they can, but they sometimes put up barriers that add to the complexity of doing research when the payoffs are in the future. We’ll all breathe a sigh of relief having this impediment removed.”—Peter Farley.

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