

Perspective: Policies must keep pace with genetic progress

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Enactment of the Genetic Information Nondiscrimination Act (GINA) of 2008 is a boon to individual patients and for genetic research, write Kathy Hudson, M.K. Holohan, and Francis Collins in the June 19 issue of the *New England Journal of Medicine*. But the bill is not a panacea, they note: Employers, health insurers, patients, and doctors now must be educated about its provisions, gaps remain in genetic testing oversight, and there still may be opportunities to misuse genetic information.

Hudson, director of the Pew Charitable Trusts-funded Genetics and Public Policy Center, and co-authors Holohan and Collins of the National Human Genome Research Institute, reflect on GINA's slow path through the legislative process. "When the first federal legislation to prevent the misuse of genetic information was introduced in 1995, many in the health care, research, and policy communities considered the measure forward-looking. Others called it premature," they write. Thirteen years later, they note, "With many of these tests becoming available in the clinic and some even being offered directly to consumers, GINA's protections could no longer be dismissed as premature; they were rapidly coming to seem essential to Americans' ability to make the most of the much-anticipated era of personalized medicine."

After spending years stalled in committees, GINA finally passed the House and Senate this spring with overwhelming bipartisan support, and was signed into law by President Bush on May 21. The bill prevents health insurers from denying coverage or setting premium rates based on

genetic information, and employers from making hiring, firing, or promotion decisions based on a person's genes.

The authors quote Sen. Edward Kennedy, who called GINA "the first major new civil rights bill of the new century." Kennedy was one of the bill's lead sponsors. "Discrimination in health insurance and the fear of potential discrimination threaten both society's ability to use new genetic technologies to improve human health and the ability to conduct the very research we need to understand, treat, and prevent genetic disease," he said.

GINA removes roadblocks in both health care delivery (because patients can take genetic tests without fear of reprisal) and research (because potential participants can be assured of the security of their genetic information), the authors explain. However, there are still regulatory steps to be taken to ensure genetic information is used wisely. "[F]ederal agencies must write the implementing regulations that will provide detailed guidance for health insurers and employers about how to comply with the new law," the authors point out. Additionally, "We need to make certain that health care professionals and patients understand the new protections."

Besides discrimination, another challenge to genomic medicine is that "There are important gaps in the oversight of genetic tests, and multiple advisory groups have called for regulatory reform to ensure the analytic and clinical validity of genetic tests," the authors write. Finally, they note, "GINA addresses only employment and health insurance, not life insurance, disability insurance, or long-term care insurance... It may well be time for a thoughtful evaluation of these other realms that are likely to be touched by the swift advance of genomic science."

Source: Genetics & Public Policy Center, Johns Hopkins University

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