

## Beyond GINA

### To the editor:

With the signing by President Bush last month of the Genetic Information Non-Discrimination Act (GINA), almost two decades of research, policy initiatives and legislative work in the US have come to fruition. The first policy initiative of the Ethical, Legal and Social Issues component of the Human Genome Project has finally engendered a landmark post-genomic law. There is now a safety net intended to protect the valuable personal information that has arisen from human genomics.

As we gain deeper understanding of DNA and gene effects on health and disease, insurers, employers, governments, companies and other entities have asserted their interest in using genetic information in their processes<sup>1</sup>. The new legislation sets limits on this activity while protecting the public's good—allowing individuals to avoid substantial burdens in knowing their own genetic information and thus allowing for the prevention of diseases with substantial genetic influences when possible and desired, while adjusting more fruitfully to disease risks that are not preventable. The legal protections against genetic discrimination can begin to erase the fears individuals may have in knowing and acting on genetic health risks.

It has been 15 years since my collaborators and I first published research documenting incidents of genetic discrimination occurring in the US and the broad adverse consequences of this discrimination<sup>2,3</sup>. What will happen now that legal protections are in place? In the short term, probably not much will change. Several US states have already issued protective local laws, some of which are farther reaching than the federal law just signed. GINA, for instance, does not eliminate disease-based discriminatory practices, nor does it offer protection for those seeking life or disability insurance contracts. Many corporations, including insurance companies and genetic testing providers, have responded to holes in the federal law and already have strong nondiscrimination policies.

Lawsuits, like the landmark cases linked to inappropriate testing at Lawrence Berkeley National Laboratories and the Burlington Northern Railroad<sup>4</sup>, may arise. The informed consent that people give before participating in genetic research or before clinical testing should change to take stock of the federal protections. And the pall cast by discrimination—and its impact on test adoption by the market—may lift from biotech companies offering genetic diagnostics. If effective, the new legislation may improve the prospects for this health-related market and for genetically informed care.

The big boon for genetic testing in the US will come first when its clinical utility, with personal and public value, is shown, and then by

its incorporation into the practice of medicine. By participating in clinical research and adopting testing by direct-to-consumer distribution early, consumers will probably have an important role in this process. Lessening concerns about adverse discrimination, this law will enable greater consumer involvement in the evolution of genetically informed testing.

But this legislation is not a panacea for genetic discrimination. Laws guaranteeing civil rights in the US have not ended racial discrimination. To become truly free of genetic discrimination, a generation or longer of enlightened understanding of our biological diversity and complex ancestry, acceptance of our genetic differences and the limits of genetic determination, and improvements in the lives and care of those with genetic disorders will need to pass. Antidiscrimination laws are only effective as guideposts to better understanding and tolerance.

GINA may turn out to be a key step in the adaptation of our society to a deeper understanding of our biology<sup>5</sup>. As genomic analysis becomes more common, it should help citizens become more informed about their health status. Knowledge of individualized risks, together with effective preventive measures and a healthcare system that is all-inclusive and nondiscriminatory, should be the healthcare reform toward which we all work.

The signing of GINA is therefore important as a sentinel step in the adaptation of our society to deeper understanding of our personal genetics and as a moment of restatement of our most deeply held values. All people are created equal, and now they are also freer to understand their genetics without fear of wrongful discrimination.

### Paul R. Billings

*Member (appointment pending), Secretary's Advisory Committee on Genetics, Health and Society, United States Department of Health and Human Services, and  
President and Chief Executive Officer, Cellpoint Diagnostics, 265 North Whisman Road, Mountain View, California 94043, USA.  
e-mail: paul@cellpointdiagnostics.com*

### COMPETING INTERESTS STATEMENT

The author declares competing financial interests: details accompany the full-text HTML version of the paper at <http://www.nature.com/naturemedicine/>.

1. Khamsi, R. *Nat Med.* **14**, 589 (2008).
2. Billings, P.R., et al. *Am. J. Hum. Genet.* **50**, 476–482 (1992).
3. Billings, P.R. *Genet. Med.* **2**, 207–208 (2000).
4. French, S. *Duke Law Technol. Rev.* 5 September 2002, 0015.
5. Billings, P.R. *Nat. Genet.* **37**, 559–560 (2005).