

Jul 1 2008 (Vol. 28, No. 13)

## **GINA Provides Bioindustry Boost**

### **Companies Expect to Benefit along with Consumers and Clinical Researchers**

Sharon Terry

Joann Boughman, Ph.D.

After more than a decade of discussion about the importance of establishing a federal standard barring discrimination in employment and health insurance on the basis of genetic information, the President has signed into law a bill that addresses these key issues in American health policy.

The Genetic Information Nondiscrimination Act (GINA) brings new promise for all Americans, with particular benefits for clinical research and biotechnology. For the first time ever, individuals are able to avail themselves of genetic testing without the fear that someone will misuse their genetic information.

As founding members of the Coalition for Genetic Fairness ([www.geneticfairness.org](http://www.geneticfairness.org))—the organization that supported GINA—the American Society of Human Genetics ([www.ashg.org](http://www.ashg.org)) and Genetic Alliance ([www.geneticalliance.org](http://www.geneticalliance.org)) played a role in educating Congress and the public about GINA.

The chief purpose of this legislation is to protect the privacy of Americans' personal genetic information and to prevent genetic discrimination involving decisions about employment and health insurance coverage made on the basis of an individual's genetic testing or screening results.

Specifically, the new GINA statute will:

- Prohibit medical insurance companies from basing coverage eligibility or adjusting premiums on the basis of an individual's genetic information;
- Prohibit insurance companies from requesting that applicants for health coverage plans be subjected to genetic testing or screening, and prohibit them from discriminating against applicants based on their personal genetic information;
- Prohibit employers from using genetic information to refuse employment, and prohibit them from collecting employees' personal genetic information without their explicit consent.

#### **National Standard**

Although more than 40 U.S. states have some form of genetic nondiscrimination legislation in place, the current regulatory landscape is a patchwork of insurance and employment protections that varies from state to state. The passage of GINA establishes a minimum national standard for all healthcare insurers and employers. It is important to note, however, that some states have more restrictive laws that will still remain in effect.

In the recent past, fear of discrimination has deterred a significant number of people from having medically-indicated genetic testing and screening procedures performed, and it has also kept families and individuals from volunteering to participate in genetic research studies and clinical trials.

Now, with the GINA legislation, these concerns will be largely alleviated, which means that at-risk individuals may now take advantage of predictive genetic testing that will inform the development of practitioners' plans for early screening, diagnosis, and intervention for many diseases with a genetic component (such as cancer, heart disease, diabetes, and depression).

As scientists continue to make rapid advances in genetic research and technology, clinicians will be expected to keep up with the latest research findings in human genetics and to apply new knowledge and innovative tools in healthcare practice to personalize or tailor interventions and treatments according to an individual's genetic profile.

With the recent passage of GINA, it is now possible for patients and their families to take advantage of new tests and assessments in a manner that ensures the full realization of personalized medicine models. Thus, we expect that the use of predictive genetic testing and screening procedures in personalized medicine will inevitably become a more common practice and an integral part of medical care.

These changes in our nation's genetic research and healthcare system, brought about by the GINA legislation, will have a significant impact on, and implications for, the biotech industry. We believe that biotech companies will become even more central to the process of translating advances in genetic research and technology to healthcare practice.

With more Americans willing to participate in clinical trials there will likely be an increase in human genetics research projects, which will, in turn, mean an increase in market demand from scientists who wish to purchase the tools, technologies, and services produced by biotech companies; conditions that are necessary to complete their research.

Now that the GINA bill has been signed into law, Americans can participate in clinical trials and appropriate genetic testing and screening procedures unencumbered by the fear of discrimination based upon the results. We are pleased that the federal government has finally established a national standard of protection for the American people to protect the privacy of their personal genetic information and to prevent and eradicate genetic discrimination.

With the recent federal passage of GINA, the message is now unambiguous: the misuse of genetic information resulting in discrimination in employment or health insurance decisions is against the law in the United States.

Sharon Terry (sterry@geneticalliance.org) is president and CEO of the Genetic Alliance. Web: [www.geneticalliance.org](http://www.geneticalliance.org). Joann Boughman, Ph.D., is evp of American Society of Human Genetics. Web: [www.ashg.org](http://www.ashg.org).



- [Email](#)
- [Print](#)
- [Email the Editor](#)
- [Reprints & Permissions](#)
- [Back](#)

### Comment on this Article:

Name:

Title:

Comment: