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**Are You Ready
to Find
Your Next Job?**

U.S. Law Bans Genetic Discrimination

BY JOHN R. PLATT

If you have relatives with a history of hereditary conditions like Parkinson's disease, diabetes, or breast cancer, would you want to know if you were genetically inclined to develop the diseases yourself?

Of more concern, would your employer or your medical insurer want to know, and if so, what would they do with that information? Would they use it perhaps to terminate your employment or cancel your insurance coverage?

U.S. citizens no longer need worry about such discrimination, thanks to the Genetic Information Nondiscrimination Act (GINA), signed into law on 21 May 2008. The law prevents medical insurers from changing, cancelling, or denying coverage based solely on a person's genetic predisposition to a disease or disorder. GINA also prevents employers from basing decisions about hiring, firing, and promotion on genetic information.

The bill, which took 13 years and several iterations to pass, had long been supported by IEEE-USA.

"We thought it was worthwhile for our members and our country," says Frank E. Ferrante, former chair of IEEE-USA's Medical Technology Policy Committee, which supported the act on IEEE's behalf. "We wrote letters and policy statements to key representatives in the House and Senate. That's what our committee does—we back positions and go to Capitol Hill and try to get things done."

Ferrante, who still serves on the committee, recalls that its support of GINA "really kicked off" when, at a meeting to garner support for the act, fellow committee member Mark O'Leavey used a metaphor comparing the protection of personal medical information with the behavior of adult tilapia fish: "Tilapia parents protect their young by drawing them into their mouths—protecting those that cannot be protected otherwise." The GINA law works the same way, Ferrante says, offering individuals protection within a much larger system.

A FIRST The GINA legislation is the first U.S. federal protection of its kind, according to Joann Boughman, executive vice president of the American Society of Human Genetics and a member of the executive committee of the Coalition for Genetic Fairness, Washington, D.C., an

alliance of advocacy groups that supported the bill.

“Thirty-seven U.S. states currently have some sort of protection on the insurance side, but if someone moves from state to state, the protection changes,” Boughman points out. “We wanted to remove the ambiguity,” she says. This was accomplished by making GINA an employment law, which is prescribed on the federal level, as opposed to insurance laws, which are enforced at the state level.

Few countries have protections similar to those offered by GINA, notes Boughman. “Some policies and rules are on the books in the UK and Australia, as well as in some other EU countries. But those countries all have less complex laws on the insurance side compared to the United States because they offer universal [health] coverage,” she says.

HUNDREDS IN SUPPORT The GINA law passed in part because several hundred organizations were behind it, including IEEE-USA, says Boughman. “Having that many supporters—of all kinds—sent a message to the Senate about how important this was. It was especially important to have professional organizations like IEEE-USA in our support base.”

For more information on GINA, visit <http://www.geneticfairness.org>.

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