

Over a decade ago, I first introduced a bill aimed to protect the people of this country from health insurers or employers using genetic information for insurance coverage decisions, hiring, firing, job placement, or promotion decisions. After languishing in past Congresses, a new leadership in the House passed H.R. 493, the Genetic Information Nondiscrimination Act (GINA) on April 25th with an extraordinarily bipartisan vote of 420 to 3.

Since I first introduced the bill those many years ago, the need for GINA has grown exponentially. Today, we find ourselves on the verge of some of the most stunning breakthroughs in modern medical history. The completion of the human genome enables researchers to identify genetic markers for a variety of chronic health conditions, offering a new approach to treat and prevent diseases. But without federal safeguards in place, the promise of genetic research will not be realized. To benefit from gene-based medicines, the public's fear of genetic discrimination must be eliminated -- and Congress has a responsibility to help alleviate the public's concerns.

These concerns are no longer the work of science fiction writers. There have been many instances of genetic discrimination: from a woman who was fired after a genetic test revealed her risk for a lung disorder - to a social worker, who despite outstanding performance reviews, was dismissed because of her family history of Huntington's disease. And just a few years ago, the House of Representatives heard powerful testimony from a woman who was denied health coverage for her two children on the basis that they were carriers of alpha-1 antitrysin disease. Carriers typically do not exhibit symptoms of the disease and with the help of advocates and the press, the insurance company reversed its decision.

Bottom line – everyone has bad genes and thus, is a candidate for discrimination. What is more important, the unease the public feels concerning how their genetic information will be used has a deeply negative impact on public health. If individuals are afraid of suffering discrimination at the hands of employers and health insurance companies, they will be less likely to get a genetic test and receive needed preventative treatment.

In a 2006 Cogent Research poll, 66% of respondents reported concerns about storage and access to their genetic information; 72% agreed that the government should establish laws and regulations to protect the privacy of their genetic information; and 85% said that employers would use such information to discriminate unless current laws were amended.

There is not a single person on this planet that carries with them perfect genes – every one of us carries a predisposition to illnesses. In fact, each person is estimated to be genetically predisposed to between 5 and 50 serious disorders. This is exactly why GINA is important to all of us, not just those with manifested diseases or disorders.

GINA will do more than stamp out a new form of discrimination - it will help our country be a leader in a field of scientific research that holds tremendous promise and it will allow Americans to make better decisions to improve their health.