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Your Genes and Privacy

THE GENETIC INFORMATION NONDISCRIMINATION ACT (GINA) LANGUISHED IN past Congresses for 12 years. But finally, new leadership in the House of Representatives has given the bill its best chance to become law since its introduction in 1995. On 25 April, GINA passed the House by a vote of 420 to 3. The act will prohibit health insurers from denying coverage or charging higher premiums to a healthy individual solely because they possess a genetic predisposition to develop a disease in the future. It will also bar employers from using genetic information in hiring, firing, job placement, or promotion decisions.

Over time, the need for GINA has only grown. We stand on the verge of some of the most stunning breakthroughs in modern medical history. The completion of the sequencing 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. Fear is the obstacle that must be overcome: fear that our personal genetic information could be abused and prevent us from getting the health insurance we need and the jobs we want. To benefit from gene-based medicine, the public's fear of genetic discrimination must be eliminated, and Congress has a responsibility to help allay the public's concerns.

Instances of genetic discrimination in the United States have already occurred. In the 1970s, many African-Americans were denied jobs, educational opportunities, and insurance based on their status as carriers of sickle cell anemia. In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge during an attempt to undermine a worker's compensation claim by proving that carpal tunnel syndrome has a genetic basis. And in 2004, a U.S. Department of Health and Human Services committee heard powerful testimony from victims of workplace and insurance discrimination. As a result of cases like these, public concern is palpable: In a 2006 survey, 66% of respondents reported worries about storage of 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 law was amended.

Genetic discrimination is, of course, inherently unjustifiable and illogical. Having a genetic predisposition to a disease in no way guarantees that it will develop, and virtually all of us have some bad genes that could potentially manifest in illness. As a result, discrimination based on one's genetic makeup alone could logically be extended into a form of discrimination against everyone. But what is more, 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 insurance companies, they will be less likely to get genetic tests and receive needed preventative treatment. In the cases of breast or colon cancer, this could mean life or death.

Perhaps worst of all, genetic research is being stifled. Large samples of individuals must participate in genetic research studies to make them valid, and potential participants will hesitate if they fear losing their jobs or health insurance. Francis Collins, head of the National Human Genome Research Institute, and James Watson called attention to this problem in a 2003 *Science* editorial, writing that genetic discrimination will "slow the pace of the scientific discovery that will yield crucial medical advances" by resulting in studies based on "a self-selected group that could skew research results."

The responsibility of Congress to address the threat posed by genetic discrimination makes GINA's recent passage in the House significant. Because similar bills have already been approved by the Senate on two previous occasions, and because President Bush supports the proposal, its future looks bright. On the day that GINA is signed into law, an insidious form of discrimination will disappear, opening the door to a field of scientific research that holds as much promise as any in medical history.

— Louise M. Slaughter

