Genetic Discrimination: Time to Act

Coinciding with the completion of the Human Genome Project and the 50th anniversary of the discovery of DNA’s double helix in April, the U.S. National Human Genome Research Institute (NHGRI) set forth a bold vision for the future of genomics research.* The plan primarily focuses on translating genomic research into health applications. Now, however, the fate of one crucial element needed to realize this vision lies not with scientists but with the 435 members of the U.S. House of Representatives. The House needs to approve the Genetic Information Nondiscrimination Act of 2003 as soon as possible. This groundbreaking bill would protect U.S. residents from genetic discrimination in health insurance and the workplace, and it was passed by the U.S. Senate on 14 October by a landslide vote of 95 to 0.

Let no one think that this is an issue that affects only rare individuals. All of us carry dozens of glitches in our DNA sequence, yet no one should be denied a job for which they are otherwise qualified because of the genes they inherited. No one should be denied health insurance because of predispositions found in their DNA. Genetic discrimination has the potential to affect people’s lives in terms of jobs and insurance, but there is another dimension as well: It can slow the pace of the scientific discovery that will yield crucial medical advances. We know that many people have already refused to participate in genetic research for fear of genetic discrimination.† Without protections in place, individuals who do agree to participate will represent a self-selected group that could skew research results, producing a negative impact on all of us who look to genetics to help find better ways of diagnosing, treating, and preventing disease. Furthermore, the health system will be at risk if patients are reluctant to undergo genetic testing or elect to keep genetic information out of their medical records because of very real concerns about discrimination. The longer this problem remains unresolved, the greater the damage that will be done to U.S. science and medicine.

Thanks to the dedicated efforts of scientists, disease advocates, health care professionals, and lawmakers, we now stand on the verge of attaining the long-sought goal of safeguarding the private genetic information of all Americans. Since 1995, when the NHGRI and the Department of Energy convened a working group to discuss the issue of genetic discrimination, we have witnessed many attempts to draft legislation on this issue. That group published pioneering recommendations in this journal on preventing discrimination,‡§ many of which are reflected in the bill that has been passed by the Senate and is now before the House. The legislation’s main provisions would prevent health insurance companies from requiring a genetic test, would block them from collecting genetic test results from other sources, and would prevent the use of predictive genetic information to increase premiums or deny coverage in the individual and group markets. In addition, employers would not be allowed to ask for genetic information about employees nor to use that kind of information as part of a hiring or promotion decision. Companies would, however, be allowed to use genetic testing as a method for monitoring scientifically validated health risks from hazardous chemicals in the workplace.

From our perspective, the Genetic Information Nondiscrimination Act of 2003 is an outstanding effort that successfully addresses the myriad concerns of the biomedical research and health communities. As pointed out so eloquently by members of both parties who supported this bill in the Senate, this is a civil rights issue. Without the clear, strong safeguards that this bill provides, many in the public will be reluctant to enter into the genome era, and we will not fully reap the rewards of the investment already made in human genome research. It is only fitting that in 2003, a year filled with historic DNA milestones, the U.S. Congress and the president move forward together to give a present to the American people: enactment of a nondiscrimination law protecting all of us.

Francis S. Collins and James D. Watson

The House should approve the Genetic Information Nondiscrimination Act of 2003 as soon as possible.

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Science 302 (5646), 745.
DOI: 10.1126/science.302.5646.745