Genetic Discrimination: Time to Act

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ciding with the completion of the Human Genome Project and the 50th anniver-
sary 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 ge-
nomics 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 dis-
crimination 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 predis-
positions found in their DNA. Genetic discrimination has the potential to af-
fect people’s lives in terms of jobs and insurance, but there is another di-
mension as well: It can slow the pace of the scientific discovery that will
yield crucial medical advances. We know that many people have already re-
fused 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 com-
munities. 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.

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