

# The American Society of Human Genetics

## Policy Statement

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December 18, 2001

### **The Board of Directors of the American Society of Human Genetics has endorsed the Genetic Nondiscrimination and Health Insurance and Employment Act**

The Board of Directors of the [American Society of Human Genetics \(ASHG\)](#) has endorsed U.S. Senate Bill 318, the Genetic Nondiscrimination and Health Insurance and Employment Act.

ASHG is the primary professional organization for human geneticists, representing nearly 8,000 researchers, physicians, laboratory professionals, counselors, and nurses engaged in genetics discovery, teaching, and genetics health care applications and services.

ASHG is keenly aware of the challenges faced by individuals and families involved in genetic evaluation and diagnostic procedures. Many of us have personally experienced cases in which testing or its outcome led to adverse effects on employment or on insurance qualifications or affordability, or witnessed situations in which concerns about the possibility of discrimination have affected choices to be tested or forced testing to be done outside the context of a health care plan. The potential for inappropriate use of genetic information by insurance carriers or employers has also been an impediment in recruiting subjects for some research studies.

Many states have enacted some form of genetic anti-discrimination legislation. Because state laws are quite varied in their scope and focus of coverage, the ASHG supports federal genetic nondiscrimination legislation that would assure families in our mobile society that neither health care coverage nor employment status could be adversely affected by the results of genetic testing in which they participated.

As the study human genetics rapidly advances, genetic testing will become a routine step in many evaluation procedures. We must be assured that all individuals are appropriately protected during genetic testing, including: (1) those who have a genetic disorder, or genes associated with the development of a disorder; (2) persons with a genetic diagnosis who are currently asymptomatic, including those for whom interventions might delay onset or reduce symptom progression; (3) relatives of affected individuals who are at risk and may wish to be tested for a genetic predisposition; and (4) persons volunteering to participate in genetic research projects.

While other legal and regulatory mechanisms may become available, the most expeditious manner to address the concerns of the public is to enact the legislation that has gained substantial bipartisan support. This legislation would provide a timely response to very real and growing concerns, and remove an impediment to research into genetic diseases. At a time when rapid scientific advances are being made, delay in implementation of policy or legislation will increase the chances that many more incidents of discrimination will occur. Therefore, ASHG urges prompt legislative attention in this very important matter.

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