Genetic Discrimination in Health Insurance and Employment

GENETIC ALLIANCE
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With completion of the genome mapping and the dawn of the new genomic revolution, we must appreciate the enormous personal impact of genetic information on everyone. Already there are individuals and families whose lives have been changed in profound ways by the potential of genetics for improved health.

On the frontlines of genetics, however, there are also individuals and families who are confronting problems with discrimination in employment and health insurance. There are already growing numbers whose personal genetic information has been used, without authorization or awareness, to make critical decisions affecting the cornerstones of their lives – health insurance and employment.

The Genetic Alliance is the largest international genetics coalition worldwide, representing more than 300 lay advocacy, professional and corporate organizations and their millions of members. Dedicated to promoting healthy and full lives for everyone impacted by genetics, the Alliance works to speed the translation of genetics from the lab bench to the bedside through a range of public policy, information and educational services. Fourteen years of collaboration with support and professional organizations and operation of a Genetics Helpline has given the Genetic Alliance unique insight into genetic discrimination issues.

The Genetic Alliance suggests that these principles are central to understanding the profound implications of genetics:

• Genetic conditions are universal. Every man, woman and child has some genetic predisposition, condition or disease resulting from inherited or acquired genetic changes.

• Genetic information is inherently personal and must be treated as confidential and proprietary.

• Access to health care, education and employment is essential to all individuals, regardless of genetic inheritance.

Given the rapid pace of new genetic technologies, discrimination is a problem that threatens to grow over the next few years. Currently, tests are available for approximately 700 genes, most of which are associated with relatively rare conditions. That small number will soon grow to the thousands, providing the ability to identify predispositions and susceptibilities to many common health problems. Since each individual carries a number of mutated genes, genetic discrimination and issues of privacy threaten each of us.

Establishing genetic nondiscrimination protections in the workplace and in healthcare is an important first step towards protecting access for all Americans to employment and health
services regardless of their genetic inheritance. Current Federal laws do not prohibit employers and insurers from making decisions about employment and health insurance coverage based on an applicant’s genetic information. State legislation, where it exists, makes up a colorful, complex and inadequate patchwork of definitions, punitive action and other terms.

The Genetic Alliance supports the principle that employment and health insurance decisions should be based on an applicant’s demonstrated qualifications, performance and ability to do the job. Given the current status of genetic research and technologies, test results and diagnoses are inadequate measures of future productivity or health costs.

As the public confronts these issues, it is important to remember that:

• People make major life decisions to avoid the risk of discrimination. Perceived risk of discrimination can lead to refusals of genetic testing to safeguard employment and health insurance, sometimes with significant health consequences.

• If fears of discrimination result in significant decline in research participation, the full promise of today’s genetic discoveries will not be seen.

• We all possess imperfect genetic inheritances that will become equally and increasingly transparent with tomorrow’s technologies.

• The exclusion of individuals from jobs and health services on the basis of their genetic make-up risks the creation of an uninsurable and unemployable subclass at enormous financial, public, and moral costs.

Completion of the genome is a wonderful and inspiring scientific accomplishment. This new science is moving so fast, however, that it is accelerating the need for universal protections. Assurances against the misuse of personal genetic information will safeguard our hopes for improving public health through new genetics knowledge and technologies. In their absence, the remarkable achievements of the Human Genome Project will be rendered meaningless.

The Genetic Alliance calls for the unequivocal prohibition of genetic discrimination in health insurance and employment. Every American – regardless of genetic inheritance – deserves the protection that Federal legislation alone can provide.