



AMERICAN ACADEMY *of* ACTUARIES

February 16, 2007

The Honorable Nancy Pelosi
Speaker of the House
H-232 U.S. Capitol Building
Washington, DC 20515

Dear Madam:

On behalf of the American Academy of Actuaries' ¹ Health Practice Council, I am writing to you regarding the use of genetic information. Legislation that would regulate the use of genetic information, *Genetic Information Nondiscrimination Act of 2007* (H.R.493), particularly with respect to health insurance, has recently passed the House Committee on Education and Labor. As this legislation is considered, it is important that policy-makers have a clear understanding of issues related to genetic information in order to balance the concerns of the public, the predictive ability of the genetic test results, and the affordability of health insurance.

There is broad agreement that the confidentiality of sensitive health information must be protected. Genetic information is subject to the same confidentiality rules as are other forms of health information. While there may be particular sensitivities in the case of genetic information, it is part of the broader issue of health information confidentiality. The possible future use of genetic information for underwriting medical expense insurance is a potentially significant issue only in the voluntary individual health insurance market. In that market, however, there is a concern that a ban on the use of any genetic information – particularly if the definitions are too broad – could conflict with the principles that underlie the financial soundness of that market.

Risk classification, which is the process by which applicants for insurance coverage are placed into groups with roughly equivalent levels of risk to ensure their premium cost is commensurate with their risk level, is key to the soundness of the voluntary individual medical expense insurance market. Voluntary markets operate most efficiently when there is equality of information among buyers and sellers. But, individuals who know, or suspect, that they have genetic disorders fear that this information could be used to deny or terminate their insurance coverage. A ban on the use of genetic information that would prohibit insurers from asking for genetic tests may remove applicants' fears of genetically based denial of coverage. However, barring insurers from obtaining test results already known to the applicant could result in an imbalance of information that would leave insurers at a disadvantage. Such

¹ The American Academy of Actuaries is a national organization formed in 1965 to bring together, in a single entity, actuaries of all specializations within the United States. A major purpose of the Academy is to act as a public information organization for the profession. Academy committees, task forces and work groups regularly prepare testimony and provide information to Congress and senior federal policy-makers, comment on proposed federal and state regulations, and work closely with the National Association of Insurance Commissioners and state officials on issues related to insurance, pensions and other forms of risk financing. The Academy establishes qualification standards for the actuarial profession in the United States and supports two independent boards. The Actuarial Standards Board promulgates standards of practice for the profession, and the Actuarial Board for Counseling and Discipline helps to ensure high standards of professional conduct are met. The Academy also supports the Joint Committee for the Code of Professional Conduct, which develops standards of conduct for the U.S. actuarial profession.

asymmetric information between the insurer and the applicant could result in adverse selection that would have a direct impact on premium rates, ultimately raising the cost of insurance to everyone.

As genetic tests become increasingly available, the question of whether a positive test result on a genetic test constitutes a preexisting condition will arise. Currently, for employer-sponsored health plans, HIPAA specifies that if genetic information is used to screen for a genetic predisposition to disease, and is not related to a diagnosis, it may not be treated as a preexisting condition. A similar approach might be appropriate for individually purchased medical expense insurance.

Additionally, any proposal to regulate the use of genetic tests and genetic information should provide a clear definition of the tests being regulated, since the scope of such a definition could have a significant impact on both consumers and insurers. The underwriting process in the individual medical expense market would be severely hampered if prohibited genetic tests were broadly defined to include information obtained from physical exams or routine laboratory testing, for example.

Guaranteeing all Americans access to medical expense insurance, while preserving the viability of a voluntary system of individually purchased insurance, are difficult but important challenges for policy-makers. While most Americans are guaranteed access to some form of medical expense insurance, the cost of coverage varies significantly, and there are still some gaps. Filling those gaps could help reduce the potentially adverse impact of genetic testing on an individual's future ability to purchase medical expense insurance.

The American Academy of Actuaries' Health Practice Council has developed a series of documents to provide education on the actuarial aspects of the complex issues related to genetic information and risk classification. The following are available on the Academy's website at <http://www.actuary.org/health/index.htm>:

- Testimony before House Education and the Workforce Subcommittee on Employer-Employee Relations: *Genetic Nondiscrimination: Examining the Implications for Workers and Employers* (July 2004)
- *The Use of Genetic Information in Disability Income and Long-Term Care Insurance* (Spring 2002)
- *Risk Classification in Voluntary Individual Disability Income and Long-Term Care Insurance* (Winter 2001)
- *Genetic Information and Medical Expense Insurance* (June 2000)
- *Risk Classification in Individually Purchased Voluntary Medical Expense Insurance* (February 1999)

The Academy's Health Practice Council neither endorses nor opposes any of the specific legislative proposals under consideration; rather, we seek to provide objective actuarial analysis of the issues. We appreciate your efforts to deal with these complex and important issues and hope you find our materials helpful as this debate continues.

If you have any questions, or if you would like copies of any of our publications, please feel free to contact Heather Jerbi, the Academy's senior health policy analyst (federal) at (202) 785-7869 or jerbi@actuary.org.

Sincerely,

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American Academy of Actuaries