



AMERICAN ACADEMY *of* ACTUARIES

May 22, 2003

Dear Senator:

I am writing on behalf of the American Academy of Actuaries'¹ Health Practice Council regarding the use of genetic information. Legislation has been introduced in both the House and Senate that would regulate the use of genetic information, particularly with respect to 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, this 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 market. However, in that market, 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 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 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.

¹ The Academy is the public policy organization for actuaries of all specialties within the United States. In addition to setting qualification and practice standards, a major purpose of the Academy is to act as the public information organization for the profession. The Academy is nonpartisan and assists the public policy process through the presentation of objective analysis. The Academy regularly prepares comments on proposed federal regulations, and works closely with state officials on issues related to insurance. The Academy also develops and upholds actuarial standards of conduct, qualification and practice, and the Code of Professional Conduct for all actuaries practicing in the United States.

Guaranteeing all Americans access to medical expense insurance, while preserving the viability of a voluntary system of individually purchased insurance, is a difficult but important challenge for policy-makers. A clear understanding of issues related to genetic information is needed so that proposals regulating the use of genetic testing information can find the best balance between the concerns of the public, the predictive ability of the genetic test results, and the affordability of health insurance. 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. The following documents are available on the Academy's website at <http://www.actuary.org/health/index.htm>:

- *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 Life Practice Council has also published the following two documents on this topic, which are available on the web at <http://www.actuary.org/life/index.htm>:

- *Genetic Information and Voluntary Life Insurance* (Spring 1998)
- *Risk Classification in Voluntary Life Insurance* (Spring 1997)

On August 29, 2001, the Academy also hosted a Capitol Hill briefing on genetic testing. A webcast of the briefing as well as other pertinent material are available on the Academy's website at http://www.actuary.org/briefings/genetic_082901.htm.

The Academy has not endorsed or opposed 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 or your staff have any questions, or if you would like copies of any of our publications, please feel free to contact me through Academy senior health policy analyst (federal) Holly Kwiatkowski at (202) 223-8196 or kwiatkowski@actuary.org.

Sincerely,

Janet M. Carstens, FSA, MAAA, FCA
Vice President, Health Practice Council