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May 19, 2006

Congresswoman Judy Biggert  
1317 Longworth House Office Building  
Washington, DC 20515

Dear Congresswoman Biggert:

The Committee on Science and the Law of the Association of the Bar of the City of New York writes to you, as sponsor in the House of Representatives, to express strong support for H.R. 1227, The Genetic Information Nondiscrimination Act of 2005, the Senate version of which (S. 306) has already been passed unanimously.

The term "personalized medicine" is frequently used to describe the impact that increasing our understanding of the relationship between genotype and disease will have upon the direction of health care delivery. The potential of personalized medicine to reduce the costs and to improve the social equity of health care delivery is real and significant. It includes the ability to identify patients at risk and to respond by preventing or diagnosing early to reduce the number of patients with chronic disease. However, the potential for misuse and abuse of genetic information is also real, and must be addressed in a comprehensive way at the outset if the potential benefits of biomedical advances that are based on genetic information are to be realized without sacrificing fundamental individual privacy, employment and economic rights and interests.

The current patchwork of laws in this area does not ensure that an individual's genetic information is protected. State laws vary dramatically, and those federal laws that do apply, do not explicitly address "genetic information." There is evidence that the lack of a comprehensive legal framework to protect against discrimination is having a chilling effect upon participation in studies and clinical trials (*See*, Proceedings of the U.S. Department of Health and Human Services Secretary's Advisory Committee on Genetics, Health and Society, Monday, October 18, 2004). This could have a negative effect on the advancement of medicine (*See*, Comments by Dr. Francis S. Collins, M.D., Ph.D., Director, National Human Genome Research Institute, Regarding the Passage of Genetic Information Nondiscrimination Act of 2005 (S. 306), February 17, 2005).

H.R.1227, companion bill to S.306, passed by the Senate last year, is an important step in protecting the vital rights and interests of individuals and employees and in promoting the integration of cost-effective personalized medicine into health care delivery in an ethical and non-discriminatory manner. Paramount among discrimination concerns with respect to the availability of genetic information are its possible use by insurers as a basis for denying, limiting, or canceling health insurance coverage, and its potential use by employers against employees or prospective employees.



H.R.1227 addresses both these areas of concern and will provide national uniform protection that should allow individuals to take advantage of genetic testing, research and the potential therapeutic benefits that may flow from genetic-based biomedical advances without fear of compromising or being denied health care coverage or employment opportunities.

With respect to health insurance, sections 101 through 104 of H.R.1227 expand the current protections of the Health Insurance Portability and Accountability Act of 1996, and also amend the Employee Retirement Income Security Act of 1974 and title XVIII (Medicare) of the Social Security Act. These provisions of the legislation will fill gaps in the current law that leave health insurers free to require genetic testing or to deny coverage based on genetic information. They will prohibit discrimination in eligibility or premiums for group health insurance and provide protections against the collection and dissemination of genetic information. They also prohibit issuers of individual health insurance from discriminating in eligibility or premiums based on genetic information. Very importantly, requests for or receipt of genetic services such as testing, counseling, or genetic education by an individual or a member of an individual's family are considered genetic information for these purposes, and come within the purview of the protections offered by the legislation. This protection should alleviate the fear associated with seeking genetic testing that may prove vital to an individual's future health. These protections may also lead to advances in knowledge that may benefit a much broader segment of the population. Increased participation in biomedical research studies and clinical trials will provide meaningful results in a shorter time with respect to potential breakthrough treatments and therapies.

Another important protection that will be provided by passage of H.R.1227 relates to discrimination in employment opportunities. Under the provisions of Title II of the legislation, it would be an unlawful employment practice for an employer to discriminate against any employee with respect to hiring, discharge, compensation, or terms or conditions of employment; for an employment agency to discriminate in referral of an individual for employment; for a labor organization to exclude or expel from membership in the organization or otherwise act to deprive a member of employment opportunities; or for an employer, labor organization or a joint labor-management committee controlling apprenticeship or training to discriminate against individuals in the context of admission to or employment in training, retraining, or apprenticeship programs, based on genetic information, or to require or request genetic information, except in certain circumstances such as the provision of bona fide wellness programs, or health or genetic services by the employer, labor organization, or joint labor-management committee.

Our Committee urges that this important legislation be passed in this Congressional session, and thanks you for introducing it.

Sincerely,



Andrew Mandell

CC: Hon. Samuel Johnson, Chairman  
Subcommittee on Employer-Employee Relations

Hon. Robert E. Andrews, Ranking Member  
Subcommittee on Employer-Employee Relations

Hon. Nathan Deal, Chairman  
Subcommittee on Health of the Education and the Workforce Committee

Hon. Sherrod Brown, Ranking Member  
Subcommittee on Health of the Education and the Workforce Committee

Hon. Nancy L. Johnson, Chairman  
Subcommittee on Health of the Ways & Means Committee

Hon. Pete Stark, Ranking Member  
Subcommittee on Health of the Ways & Means Committee