

Statement of Frank S. Swain before the Subcommittee on Health
Committee on Energy and Commerce
US House of Representatives
regarding the Genetic Information Nondiscrimination Act of 2007
March 8, 2008

Chairman Pallone, Representative Deal and Members of the Subcommittee:

Thank you for inviting my testimony at this hearing. There is no issue I have worked on, in my nearly 30 year professional career in legal and public policy issues in Washington, that is more important to as many people over the long and short term than this legislative proposal.

Purpose of the bill

The purpose of the legislation is quite simple. This bill will assure that highly personal genetic information, as intrinsic to the individual as skin color, and so much more significant, is not the basis for employment or insurance discrimination. It will encourage the individual to pursue any and all genetic testing and analysis which is medically prudent, untroubled by apprehension over the possibility of misuse of the information in non-medical contexts.

It is an accepted value of our society and guaranteed by law that persons may not be subject to discrimination in the workplace or insurance markets because of race or national origin. Our skin color or our parents' ethnicity are factors over which we have no control and which do not determine our ability to work hard and have a successful life. It is, however, perfectly appropriate for insurers or employers to make decisions based on our behavioral choices, whether we choose to work hard, whether we elect to smoke, skydive or pursue other risky practices.

Likewise, we are born with our 46 chromosomes and 30,000 genes. We cannot control or change them. And although we have known for 50 years that these genes were made up of a helical DNA code, we did not know what that code looked like and what it meant. Now, 50 years later, thanks to the splendid work of Dr. Collins and his colleagues, and substantial support from the US Congress and taxpayers, that human genetic code is sequenced, illustrated, mapped, for anyone to see and analyze. This era could not be more exciting at a health and disease research level or more worrying at a personal level.

Researchers now know what the genome looks like, and are plunging ahead to determine what the genes do. Reports in the research and medical literature appear daily of potential discoveries of genes associated with various health conditions. With this knowledge comes opportunity for development of cures or more efficacious treatments, perhaps personalized to the individual. But with knowledge, particularly the partial knowledge of some of this early research, comes confusion, apprehension and concern, especially for the person whose genes are being analyzed.

Context of the bill

Of the more than 1,000 genetic tests presently available, most are offered for purposes of either diagnosis of a particular current health condition, or analysis of whether a particular drug or course of treatment for a health condition will be efficacious or dangerous. Use of such manifest disease related tests is not affected by this bill. Insurance companies would be free to make

decisions on coverage and administration of payment for such tests, and analyze the utility of such tests at the individual or large group level. This bill would not affect the employer's handling of such tests, as that is already largely governed by the Americans with Disabilities Act (ADA). Once a disease is manifest, that condition cannot trigger discrimination under the ADA.

However, there are some genetic tests which merely inform whether an individual may, in the future, manifest a certain health condition. Such tests are not likely to predict exactly when the individual may show disease symptoms, the course of the disease, or how severe the particular individual's condition may be. For all but a few health conditions, it will not even dispositively predict that the individual will acquire the condition. Employer or insurer use of such individual genetic information, which may predict future disease, is not today prohibited by Federal law. It is this "gap" which the Genetic Information Nondiscrimination Act fills.

Certainty and Predictability

Individuals want to know that their own genetic maps will not be misused. Employers and insurers need reasonable and unburdensome ground rules for managing and properly using such information. This bill accomplishes both goals.

I come to this issue having served as legislative counsel to the National Federation of Independent Business for four years and having been nominated by and served President Reagan for eight years as Chief Advocate at the Small Business Administration. The concerns of small business and the small employer must always be taken seriously in any policy debate. This bill takes a responsible and modest approach.

First, most employers will not be affected at all. Genetic information is not today typically collected or acquired by employers. But with the information becoming more common, less expensive to obtain, and more easily transmittable through electronic records, the time to establish ground rules is now, before problems become widespread.

Second, the employment provisions are established within an existing body of law, whose processes, procedures and enforcement mechanisms have been well defined through decades of Congressional adjustment and administrative and judicial precedent. This bill does not depend on executive rulemaking or definitions of foggy concepts in order to become effective and predictable.

Third, employers and insurers who inadvertently acquire such information are not penalized. Thanks to an amendment adopted by the Education and Labor Committee, it should be clear that employers do not need to establish separate record keeping systems. The bill is targeted at the improper use of predictive genetic information, not the mere possession of it in whatever kind of file.

Summary

In the long run, the Genetic Information Nondiscrimination Act will be one of the most important accomplishments of this or any Congress. It will protect the individual, stimulate research, encourage treatment advances, at nearly no cost to the government or the private sector. This bill has strong bipartisan support and has been carefully reviewed and improved, reflecting many parties' input. I encourage this Committee to report the bill.

