

## **At Your Next Job Interview**

Consider the following scenario: At your next job interview the senior partner in the practice asks about your family history of hereditary colorectal cancer, then requests that you have a genetic test to define your risk. That same day, you get an irate phone call from a patient who carries a BRCA 1 mutation (which predisposes to hereditary breast and ovarian cancer syndrome) because her self-employed daughter whose mutation status is unknown has been denied health insurance. Unsavory acts on the part of employers and insurers? To most. Illegal acts? Well, that depends...

It might surprise you to find that federal laws such as the Health Insurance Portability and Accountability Act (HIPAA) of 1996 and the American with Disabilities Act (ADA) do not explicitly prohibit an employer from requiring you to take a genetic test as a condition of employment. Nor do these laws prevent private insurers in the individual market from denying insurance (or setting high premiums) based on genetic information. For the most part, genetic anti-discrimination legislation has fallen into the hands of the states. Though 47 states offer some protection from insurance discrimination, and 35 offer protections against discrimination in the workplace, some of the state laws are so narrowly drafted they do not provide meaningful protection. For example, some of the state laws exclude chemical tests and blood tests. Because all genetic tests are by definition chemical tests (and many are also blood tests), in practice these narrow laws provide no real protection against genetic discrimination. As a result, residents of the United States are only partially protected from genetic discrimination by a complicated patchwork of state laws that vary widely in scope and effect.

Despite the fact that clear-cut examples of genetic discrimination are uncommon, patients and clinicians cite the fear of discrimination as a major reason for not seeking genetic testing. In a 2007 study of 1,199 Americans by the Genetics and Public Policy Institute of Johns Hopkins University, 86% of participants expressed some or a lot of trust in their doctor having access to genetic test results. Conversely, only 24% and 16% expressed some or a lot of trust regarding their insurer and employer, respectively, having such access. The perceived risk of discrimination has had a chilling effect on the willingness of patients and clinicians to utilize genetic testing. Unresolved, the fear of discrimination represents a substantial barrier to achieving the full promise of genomics in healthcare.

The current Congress is considering a very important legislative item known as the Genetic Information Nondiscrimination Act, or GINA, which would provide specific protections against discrimination in health insurance or employment on the basis of genetic test results or family history information. GINA has had a long and interesting course, with different versions of the bill coming before Congress several times in the past 12 years (for more specifics on the legislation see the National Human Genome Research Institute's website at [www.genome.gov/24519851](http://www.genome.gov/24519851)). In both 2003 and 2005 GINA passed the Senate unanimously, but was not taken up by the House. Those opposed to GINA have cited concerns that the legislation could adversely affect the business practices of both insurers and employers by, for example, generating frivolous

lawsuits. On April 25<sup>th</sup> of this year, the House passed GINA by a vote of 420-3 and, at the time of writing, the Senate has yet to consider the bill. President Bush has indicated his intention to sign the legislation if it reaches his desk.

Whether GINA becomes law in 2007 or not, primary care providers need to discuss with their patients the relevant legal protections (or lack thereof) against genetic discrimination prior to ordering genetic testing. It remains to be seen how complex these discussions will be.