Concerns about insurance discrimination are common among patients pursuing genetic counseling and testing for hereditary cancer syndromes. Studies have consistently shown that fear of discrimination is a major reason why patients choose not to pursue genetic counseling and/or testing. This is especially true when the testing is expensive, as it often is for hereditary cancer syndromes. However, despite well-documented patient concerns and anecdotal reports of discrimination based on genetic information, there are little or no solid data to support these concerns. In fact, it has been shown that very few health insurers ask for or use presymptomatic genetic test results in their underwriting decisions. Furthermore, studies suggest that even individuals with a serious genetic condition who are presymptomatic have few, if any, problems securing health insurance.

A federal law, the Genetic Information Nondiscrimination Act (GINA) provides broad protection against genetic discrimination in group and individual health insurance and employment. This law also outlines the processes for filing claims and seeking justice for individuals who have experienced genetic discrimination.

GINA specifically prohibits issuers of health insurance (including group, individual and Medicare supplement policies) from using genetic information to:

- establish eligibility, contribution amounts and premium fees;
- specify the conditions of the policy;
- impose a preexisting condition exclusion.

GINA specifically prohibits employers, labor organizations, employment agencies and joint labor-management committees from using genetic information to:

- fire or refuse to hire an employee;
- discriminate against an employee with respect to compensation, promotions, or terms, conditions or privileges of employment;
- treat employees differently in admission to apprenticeships, training or retraining programs.

GINA also specifically prohibits employers and health insurers from requesting, requiring, disclosing or purchasing the results of a genetic test or genetic information.

While GINA is the most comprehensive law of its kind, it is important to note that it does not apply to members of the US military, veterans obtaining healthcare through Veteran’s Administration, or the Indian Health Service. It does not prohibit insurers from using current health status to determine coverage or premiums. GINA also does not apply to companies that employ less than 15 individuals.
GINA’s protections do not apply to life or disability insurance however some state laws may apply to these types of coverage.

For more information about GINA or genetic discrimination, please see the following resources:

http://www.GINAHelp.org
An online resource created by Genetic Alliance, the Genetics and Public Policy Center at Johns Hopkins University, and the National Coalition for Health Professional Education in Genetics.

http://www.geneticfairness.org/ginaresource.html
This website hosted by the Coalition for Genetic Fairness provides an overview of the Genetic Information Nondiscrimination Act (GINA).

http://www.dnapolicy.org/resources/WhatGINAdoesanddoesnotdochart.pdf
Summary chart of what is and is not covered under the Genetic Information Nondiscrimination Act (GINA) prepared by the Genetic and Public Policy Center.

Complete text of the Genetic Information Nondiscrimination Act (GINA) bill (H.R. 493).

http://www.genome.gov/PolicyEthics
This website provides a good overview of the current federal legislation as well as the various bills that have been proposed and recommendations that have been made for future legislation. It also has a policy and legislation database that is searchable by content type (i.e. type of law), topic of interest, and source (i.e. state or country).

References:
5. Community Oncology 2008;5:351-354