



## Insurance concerns: Genetic testing and discrimination Smilow Cancer Genetics and Prevention Program

Concerns about insurance discrimination are common among people pursuing genetic counseling and testing. A federal law, the Genetic Information Nondiscrimination Act (GINA), prohibits health insurance companies and employers from discriminating against people based on genetic information, including genetic test results. This law also outlines the processes for filing claims and seeking justice for people who have experienced genetic discrimination.

GINA specifically **prohibits** health insurers (including group, individual and Medicare supplement policies) from using genetic information to set eligibility, premium or contribution amounts. Under GINA, genetic information cannot be considered a pre-existing condition.

GINA specifically **prohibits** employers from using genetic information to fire or refuse to hire an employee. Under GINA, employers may not discriminate against an employee with respect to compensation, promotions, or terms of employment.

GINA also specifically **prohibits** both 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 does not apply to members of the U.S. military, veterans obtaining health care through Veteran's Administration, or the Indian Health Service. GINA also does not apply to companies that employ fewer than 15 people. It does not prohibit insurers from using current health status to determine coverage or premiums.

It is important to know that GINA's protections *do not* apply to life, disability or long-term care insurance. These companies can legally deny applications based on genetic test results.

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

- <u>http://www.GINAHelp.org</u> 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
- <u>http://www.geneticfairness.org/ginaresource.html</u> This website hosted by the Coalition for Genetic Fairness provides an overview of the Genetic Information Nondiscrimination Act (GINA)
- <u>http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110\_cong\_bills&docid=f:h493eas.txt.pdf</u> Complete text of the Genetic Information Nondiscrimination Act (GINA) bill (H.R. 493)
- <u>http://www.genome.gov/PolicyEthics</u> National Institutes of Health (NIH) website dedicated to policy and legislative issues in genomics

## **Contact information**

Smilow Cancer Genetics and Prevention Program 330 Orchard Street, Suite 107 New Haven, CT 06511 Phone: 203-200-4362 Fax: 203-200-1362 smilowcancergenetics@ynhh.org http://yalecancercenter.org/patient/specialty/genetics/