Lahey CLINIC

Frequently Asked Questions about Genetic Discrimination

Individuals who consider genetic testing often have questions about the issue of genetic discrimination. We have provided this information to answer some of the common questions regarding this topic. This is intended as an informational resource only and should not be construed as legal advice. You may have additional questions that are not included in this handout. We encourage you to contact us if you are interested in discussing this issue in more detail. We have provided our contact information and additional resources on this topic at the end of this handout.

What is genetic discrimination?
Genetic discrimination occurs when an employer or insurance company treats an individual differently based on their genetic status in the absence of current or past illness.

Should I be concerned about the possibility of genetic discrimination?
Individuals who undergo genetic testing to find out whether they have an alteration in a cancer predisposition gene may be at risk for genetic discrimination. There are some existing protections against genetic discrimination in health insurance and employment. We encourage you to discuss this issue with a genetic counselor so that you can accurately weigh the risks and benefits of genetic testing.

What are the existing federal protections against genetic discrimination in health insurance?
On May 21st, 2008 President Bush signed a bill into law called the **Genetic Nondiscrimination Act of 2008 (GINA)**. The health insurance provisions of this law went into effect in May of 2009 and the employment provisions went into effect in November of 2009. This federal law provides equal protection to all states. GINA prohibits individual and group health insurers from canceling or refusing to renew a policy or discriminating against a policyholder or applicant in length of coverage, terms and conditions, or premiums on the basis of genetic information (i.e. genetic test results, family history), or from requiring a genetic test or genetic information as a condition of coverage. Regarding employment, the law also states that an employer cannot require a genetic test or the disclosure of genetic information as a condition of employment. It is also illegal for an employer to deny or terminate employment based on genetic information.

The **Health Insurance Portability and Accountability Act (HIPAA)** was established in 1996 and provides some protection to individuals who have employer-based health insurance. The law states that genetic information cannot be considered a preexisting condition. The law also states that if an individual already has a group or individual plan, the provider cannot legally refuse to renew or continue coverage because of genetic information. If an individual changes from one health insurance plan to new group coverage, the new insurance plan cannot refuse coverage or charge higher premiums to the individual based on genetic information as long as there is not a lapse in coverage of more than 63 days.

Do the existing laws provide protection in terms of life insurance, disability insurance, or long-term care insurance?

NO. Unfortunately, current state and federal legislation does not provide protection against genetic discrimination in life insurance, disability insurance or long-term care insurance. Individuals may choose to obtain sufficient levels of life or disability insurance before they proceed with genetic testing.

Do I have to worry about genetic discrimination issues if I have already been diagnosed with cancer?

It is likely that your health insurance plan has already been alerted to the presence of a health risk based on your cancer diagnosis. Therefore, it is unlikely that genetic information known about you would increase their awareness. However, we take the same precautions with medical records for individuals who have had cancer as we do for those who are currently cancer-free. The same legal protections against genetic discrimination that are discussed above apply to individuals who have been diagnosed with cancer.

How can I learn more about this topic?

We understand that individuals may have additional questions regarding genetic discrimination. To discuss the issue of genetic discrimination in more detail, you can make an appointment to meet with a genetic counselor in the Familial Cancer Risk Assessment Center by calling 781-744-3982.

There are several websites that have additional information about genetic discrimination:

Coalition for Genetic Fairness: A Guide to the Genetic Information Nondiscrimination Act
http://www.geneticfairness.org/ginaresource.html

GINA Resources from the Genetics and Public Policy Center at Johns Hopkins University
http://www.dnapolicy.org/gina/

National Human Genome Research Institute, Genetic Discrimination Fact Sheet
http://www.genome.gov/10002328

National Conference of State Legislatures
http://www.ncsl.org/programs/health/genetics/ndishlth.htm

Genetic Alliance Resources (http://geneticalliance.org/):

- http://www.ginahelp.org/
- http://www.geneticalliance.org/sites/default/files/ksc_assets/publicpolicy/gina_information_sheet052710.pdf