

Where can I go for more information regarding genetic information and discrimination?

- Department of Health and Human Services has information on health insurance privacy and the HIPAA Privacy Rule, including how to file a complaint: www.hhs.gov/ocr/hipaa or call (866) 627-7748
- Equal Employment Opportunity Commission has information on employment discrimination, including information on how to file a complaint: www.eeoc.gov
- National Society of Genetic Counselors "Find a Counselor" resource: www.nsgc.org
- National Human Genome Research Institute has several pages on genetic discrimination: www.nhgri.nih.gov/11510227
 - ◆ information on the executive order against discrimination for federal employees: www.genome.gov/10002084
 - ◆ information on HIPAA www.genome.gov/11510216
- National Association of Insurance Commissioners has links to each state's insurance department's website: www.naic.org/state_contacts/sid_websites.htm
- National Conference of State Legislatures has resources on where to go for state laws on genetic information: www.ncsl.org/programs/health/genetics/charts.htm or call: (202) 624-5400 or (303) 364-7700

Where can I go for support or advocacy?

- FORCE: Facing Our Risk of Cancer Empowered: www.facingourrisk.org or call (866) 288-7475, extension 1
- Genetic Alliance: www.geneticalliance.org or call (202) 966-5557
- National Partnership for Women and Families: www.nationalpartnership.org
 - ◆ *Faces of Discrimination* publication can be downloaded at: www.nationalpartnership.org/library/facesofgeneticdiscrimination.pdf
- Patient Advocate Foundation: www.patientadvocate.org

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FORCE is an organization for families affected by hereditary breast and ovarian cancer and/or families in which a BRCA mutation is present

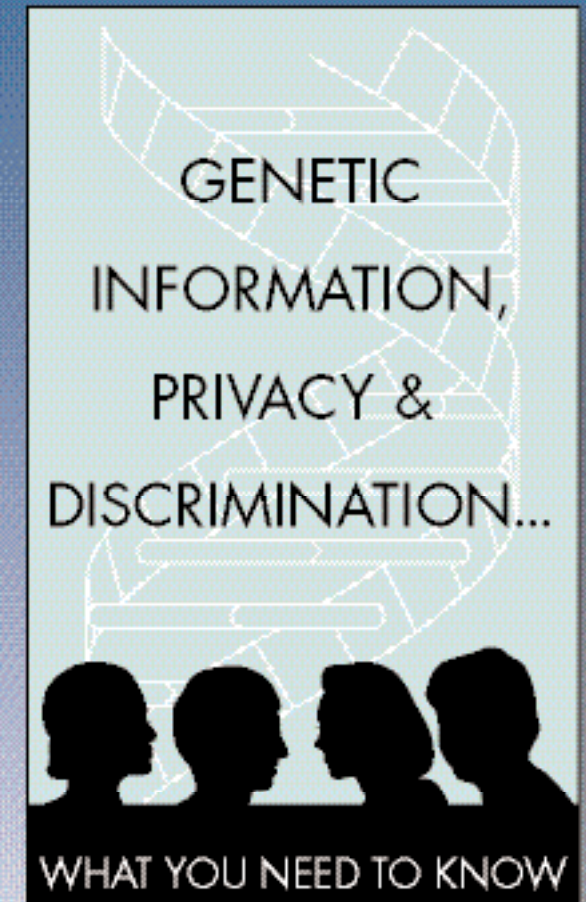
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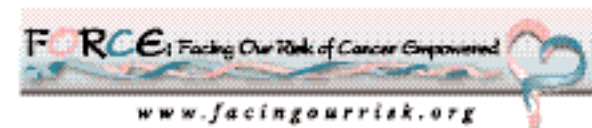


the National Society of Genetic Counselors
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NSGC is the leading voice, authority and advocate for the genetic counseling profession



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What is genetic information? Genetic information can refer to family history of a disease, a genetic test result, or the genetic test result of a family member. Every state defines genetic information differently. You may want to research and understand how your state defines genetic information.

What is genetic discrimination? Genetic discrimination occurs when a person is treated differently because he or she has an inherited disorder or is at risk to develop an inherited disorder. This brochure focuses on genetic discrimination in employment and health insurance.

Are there laws to protect against genetic discrimination?

Yes. Most states have some laws to prevent insurance companies and employers from discriminating based on a hereditary risk for disease. However, not every state offers the same protections, and some states have not yet passed laws prohibiting genetic discrimination. Because laws are constantly changing, you may want to research the most current laws in your state. There are also federal laws that offer some protection against genetic discrimination. The Health Insurance Portability and Accountability Act (HIPAA) protects people with group health insurance against being denied insurance, having their insurance canceled, or having their rates individually increased due to any pre-existing condition. For HIPAA protection to apply, an individual must have had health insurance for at least 12 months without a lapse of 63 consecutive days or longer. Although HIPAA prohibits discrimination against an individual with group insurance coverage based on any medical condition, it does not prohibit the insurance company from denying coverage to or increasing the rates of the entire group based on the medical records of one member of the group. HIPAA does not prevent insurance companies from requiring applicants to reveal whether they have had genetic testing in order to enroll in their group plans, even though the insurance companies are not allowed to use this information. Further, HIPAA laws do not provide protection to people covered by individual health insurance plans.

Federal employees have additional protection. An executive order enacted in 2000 prohibits discrimination in federal employment based on genetic information.

There are currently no federal laws providing adequate protection against life or disability insurance discrimination based on hereditary disease risk.

Is genetic discrimination a widespread problem? Documented cases of genetic discrimination are rare. In a study published in the *American Journal of Medical Genetics*, the authors found that people with inherited disorders or inherited risk were very concerned about genetic discrimination, even though documented cases were rare. They also found that there were some gaps in protection despite laws to protect individuals from workplace and insurance discrimination.^[1]

Some health care providers and advocacy groups believe that genetic discrimination could become more common if more federal laws are not enacted. In addition, there is a perception on the part of the public and some health care providers that there is a significant risk of genetic discrimination, particularly in health insurance. This perception is keeping many people from taking advantage of genetic tests that could make a significant difference in their healthcare decisions and outcomes. This fear also prevents many people from becoming involved in the medical research that could provide better information and choices for those affected by hereditary diseases in the future. In one study, researchers found that 39% of those surveyed listed fear of genetic discrimination as the most important reason for not pursuing genetic testing.^[2]

Who is at risk for genetic discrimination?

According to Dr. Francis Collins, director of the National Human Genome Research Institute, all diseases are affected by hereditary factors. "The study of the genome will reveal over the next decade the hereditary factors that contribute to virtually all common diseases, including diabetes, cancer, heart disease, mental illness, hypertension, and many others."^[3] Therefore, anyone could be at risk for genetic discrimination. Family medical history could be considered "genetic information" and could be the basis for genetic discrimination even if you have never had genetic testing. **It is important to weigh the potential benefit of a genetic test against the fear of discrimination, and it is important to base the decision whether or not to have genetic testing on credible and up-to-date information received from a specialist.** To find a genetic counselor, visit the National Society of Genetic Counselors' website at www.nsgc.org.

Who can have access to my genetic information? HIPAA has a privacy rule that requires health care professionals to notify you about your privacy

rights and how your information can be used. The privacy rule provides for the release of your medical information (including genetic test results) for certain specified purposes, including the release to insurance companies for payment. However, in most instances, the privacy rule requires your permission before your health information can be shared with individuals or organizations. **It is important to read and understand your health care providers' policies and any medical release forms before signing them.**

Some states have genetic privacy laws which offer more protection. The laws vary on what information is protected, whether a separate release must be signed before information can be shared with certain third parties and what penalties (if any) apply for violations. Because laws are constantly changing, you may want to research the most current laws in your state.

Where can I go if I feel I have been the victim of genetic discrimination?

If you feel that you have been subjected to discrimination by an insurance company based on genetic information, you can contact your state insurance commissioner's office. If you feel you have been the victim of genetic discrimination in the workplace, you can contact the Equal Employment Opportunity Commission (EEOC) which is the organization responsible for enforcing the Americans with Disabilities Act. The EEOC may be able to help some, but not all, applicants and employees who believe they have been subjected to genetic discrimination. Individuals who believe that they have faced discrimination on this basis should contact their local EEOC office. Local EEOC offices can be identified by consulting the Commission's website (www.eeoc.gov), the federal government listings in the telephone directory, or by calling a toll free information number at (800) 669-4000 or (800) 669-6820 (TDD). Be aware that strict time frames control the filing of charges of employment discrimination. Private sector employees may have as little as 180 days from the date of the alleged discriminatory act to initiate a claim. Federal government employees must contact an EEO counselor at their agency within 45 days of the act of alleged discrimination. (Source: *Communication with the EEOC*)

[1] Aileen Shinaman, Lisa J. Bain, and Ira Shoulson. "Preempting Genetic Discrimination and Assaults on Privacy: Report of a Symposium." *American Journal of Medical Genetics Part A*, 1 August 2003, p. 589-593.

[2] Donald W. Hadley, Jean Jenkins, Eileen Dimond, Kenneth Nakahara, Liam Grogan, David J. Liewehr, Seth M. Steinberg, Ilan Kirsch. "Genetic Counseling and Testing in Families With Hereditary Nonpolyposis Colorectal Cancer." *Archives of Internal Medicine*. March 2003, p. 573-582.

[3] Joseph McInerney. "Interview with Francis Collins." *The Natural Selection: Newsletter for Biological Sciences Curriculum Study*. February 2003, p. 5-8.