

What is Genetic Discrimination?

Genetic discrimination occurs when people are treated unfairly because of actual or perceived differences in their genetic information that may cause or increase the risk to develop a disorder or disease. For example, a health insurer might refuse to give coverage to a woman who has a genetic difference that raises her odds of getting breast cancer. Employers also could use genetic information to decide whether to hire, promote or fire workers. The fear of discrimination can discourage individuals from making decisions and choices that may be in their best interest. For example, a father may decide not to take a genetic test for fear of consequences to his career or the loss of insurance for his family, despite knowing that early therapy could improve his health and longevity.

Who Needs Protection?

All Canadians are affected by genetic discrimination. Every person has dozens of genetic mutations that could increase or decrease his or her chance of getting a disease such as diabetes, heart disease, Parkinson's or Alzheimer's disease. Unless this genetic information is protected, it could be used to discriminate against people.

Why is Genetic Protection Needed?

Genetic discrimination is real and growing: Cases of genetic discrimination have already been documented in Canada and are continuing to grow as more genetic information becomes available.

Genetic discrimination is unjust: it is unfair to use genetic information to determine which individuals will be employed or insured. To assume that someone's DNA will result in a disease or disorder is faulty, misleading and speculative.

Genetic discrimination concerns Canadians: Approximately 91% of Canadians feel that insurance companies should not be allowed access to their genetic information for an insurance assessment. Ninety percent of Canadians opposed the notion that employers should have access to the genetic information of workers or job applicants (Government of Canada).

Fear of genetic discrimination prevents positive uses of genetic information. Fear is preventing people from participating in genetic testing and vital research, both of which are critical to understand and treat diseases. Genetic information must be used to prevent illness and save lives and not be used against people.

History and Content of Genetic Non-Discrimination Protection

Bill S201 passed 3rd reading on March 8, 2017 and The Genetic Non-Discrimination Act (GNA) was passed into law on May 4, 2017. We should all be very proud that our community members had the courage to tell their stories and influence the protection of genetic test information for all Canadians.

For now the GNA is law and the genetic test information of all Canadians is protected. We will continue to advocate for this law so it is not overturned.

Bill S201 included the following three areas of protection:

1. **Genetic Non-Discrimination Act (GNA)**
 - a. GNA's prohibitions apply not only to providers of goods and services, but also to anyone entering into or continuing a contract with a person. This would include (among others) all employers. So anyone entering into or continuing a contract with someone is not allowed to require the person to take a genetic test or to disclose the results of a previous or future genetic test.

History and Content of Genetic Non-Discrimination Protection (Continued)

- b. GNA also prohibits providers of goods and services, and anyone entering into or continuing a contract with a person, from collecting, using or disclosing the person's genetic test results without that person's written consent. This is another basic protection of the law, in addition to the protection against someone requiring a person to take a genetic test, or disclose the results of a prior/future genetic test.

2. Amendments to the Canada Labour Code

Amendments made to the Canada Labour Code, provide an extra layer of protection for employees of federally-regulated industries; however, all employees and potential employees are protected by the basic prohibitions of GNA.

3. Amendments to the Canadian Human Rights Act (CHRA)

Amendments made to the Canadian Human Rights Act have added genetic characteristics to the CHRA.

What are the Next Steps in the Legal Process?

Today the Genetic Non-Discrimination Act stands and is law, and the amendments to the Labour Code and the Canadian Human Rights Act (CHRA) are implemented. The genetic test information of those living anywhere in Canada is robustly protected at this point in time.

The Quebec government is challenging the GNA and has referred it to the Quebec Court of Appeals. The Canadian Coalition for Genetic Fairness (CCGF) has been granted intervenor status (which means that the CCGF can intervene in support of the GNA and provide evidence to represent interests and perspectives essential to a judicial determination). The CCGF will support the GNA in the Quebec Court of Appeals.

The Canadian Human Rights Commission has also been granted intervenor status and will support the GNA in the Quebec Court of Appeals.

The Federal Attorney General, British Columbia's Attorney General and the Canadian Life and Health Insurance Association have also registered as intervenors and will oppose the GNA.

Currently, documents have been, and continue to be shared with the Quebec Court of Appeals. Verbal arguments will be presented in the fall of 2018 (the date has not yet been set).

If the Quebec Court of Appeals overturns the GNA, then it will be referred to the Supreme Court of Canada.

The GNA will remain as law unless it is overturned at the Supreme Court of Canada.

This legislation is about all genetic discrimination and the Federal Government has worked within their criminal law power to stop the harmful behaviour of genetic discrimination through this legislation that protects genetic test information.

The CCGF will continue to work with our lawyers at the Quebec Court of Appeals and if necessary at the Supreme Court of Canada to ensure this critical protection of genetic test information is not overturned.

What do People in the Huntington Disease (HD) Community Need to Know?

- The genetic test information of those living anywhere in Canada is robustly protected at this point in time (May 2018). Significant fines and prison terms can be enforced against anyone who participates in the act of genetic discrimination.
- Some clinicians are making it clear on patient files that genetic test information is protected and not to be shared without explicit written consent of the patient. In your communities, this may be a good suggestion to health care professionals. Ask your health care team about what is being done to protect your genetic test information and request that a note be placed on your medical file.
- Although everything is being done to keep the GNA legislation, there is a chance that the protection of genetic test information currently in place could be lost.
- Decisions around personal disclosure of HD and implications for genetic testing and insurance coverage need to be carefully considered and can be discussed with a genetic counsellor.

SOURCES

Government of Canada. Public opinion research on genetic information and privacy. Pollara Research, Earncliffe Research and Communications. 2003. Ottawa

RESOURCES

Ongoing support, education and information on HD is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

Fact sheets on a variety of other HD related topics are available at www.hdfactsheets.ca.

[A Physician's Guide to the Management of Huntington Disease](#)

[Understanding Behaviour in Huntington Disease: A Guide for Professionals](#)