

## 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 has discouraged individuals from making decisions and choices that may be in their best interest. For example, a father may have decided 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. Prior to genetic test information being protected by law, it could have been used to discriminate against people.

## Why is Genetic Protection Needed?

Genetic discrimination is real: cases of genetic discrimination have been documented in Canada and were continuing to grow as more genetic information became 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 created concerns for Canadians: Approximately 91 per cent of Canadians felt that insurance companies should not be allowed access to their genetic information for an insurance assessment. Ninety per cent 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 prevented positive uses of genetic information. It also deterred 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 to save lives.

## History and Content of Genetic Non-Discrimination Protection in Canada

Bill S201 passed 3rd reading on March 8, 2017 and The Genetic Non-Discrimination Act (GNDA) received Royal Assent and 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. The GNDA law protects the genetic test information of all Canadians.

### 1. Genetic Non-Discrimination Act (GNDA) Protections

- a. GNDA'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. The law also stipulates that no one may refuse to provide a good or service, or enter into a contract with a person, if that person refuses to disclose the results of a genetic test that they previously took.
- b. GNDA 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 Non-Discrimination Act (GNDA) Protections

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 GNDA.

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

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

## The Legal Steps that Followed the Passing of the GNDA into Law

The Québec government challenged the GNDA and referred it to the Québec Court of Appeals. The Canadian Coalition for Genetic Fairness (CCGF) was granted intervener status (which meant that the CCGF was able to intervene in support of the GNDA and provide evidence to represent interests and perspectives essential to a judicial determination). The CCGF supported the GNDA in the Québec Court of Appeals. The case was heard in December 2018 and the subsequent opinion of the Québec Court of Appeals was that the GNDA was not a valid exercise of Parliament's criminal law power.

This did not overturn the law but did put it at risk, which necessitated that the CCGF refer the opinion to the Supreme Court of Canada. CCGF was the appellant in the case that was heard at the Supreme Court on Oct. 10, 2019. On July 3, 2020 the Supreme Court of Canada upheld the Genetic Non-Discrimination Act. This means the GNDA remains as law and the genetic test information of all Canadians remains protected.

## 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. 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. Feel free to discuss your questions around the approach adopted by the health care professionals in your communities. Ask your health care professionals about what steps have been taken to protect your genetic test information in your medical file.
- Educate your own healthcare providers to let them know that the GNDA protects all genetic test information and it cannot be shared without your explicit consent.
- Family history of HD is not protected by the GNDA.
- Only a person's genetic test information is protected by law.

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### SOURCES

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

### RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at [www.huntingtonsociety.ca/family-services-team-list/](http://www.huntingtonsociety.ca/family-services-team-list/)

Informational fact sheets for family and friends impacted by HD are available to view, print and download at [www.hdfactsheets.ca](http://www.hdfactsheets.ca)

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at [www.huntingtonsociety.ca/hd-booklets-and-publications/](http://www.huntingtonsociety.ca/hd-booklets-and-publications/)