

# Health care implications of the Genetic Non-Discrimination Act

## Protection for Canadians' genetic information

James S. Cowan LL.D. Barbara Laine Kagedan LL.M. Gail E. Graham MD Bev Heim-Myers Yvonne Bombard PhD

In July 2020 the Supreme Court of Canada (SCC)<sup>1</sup> upheld the constitutionality of Canada's Genetic Non-Discrimination Act (GNDA),<sup>2</sup> a law that was enacted in 2017 but under a cloud, as its opponents contested it in the courts. The SCC's decision established that the law and its protections of Canadians' genetic test information are valid and apply to everyone, across the country.

Consequences of these challenges, however, were uncertainty and confusion among the public and medical community as to the nature and scope of their protection from genetic discrimination. This article explains the provisions of the law so that clinicians are equipped to protect patients' rights and understand their own responsibilities under the law.

### Why is the GNDA important?

Health care providers in virtually every area of medicine—family practice, internal medicine, pediatrics, and surgical oncology, to name a few—are increasingly using genetic testing in their practices. According to Dr Cindy Forbes, a family physician and past president of the Canadian Medical Association who spoke to the House of Commons Standing Committee on Justice and Human Rights in 2016:

Six out of every 10 Canadians will be affected during their lifetime by a health problem that is genetic in whole or in part. It's important to recognize that genetic testing will no longer be limited to rare, esoteric genetic diseases occurring in patients seen by a handful of specialists across the country. Rather, it's becoming an integral part of broad medical care and, as such, is expected to become mainstream medicine.<sup>3</sup>

However, until recently, a person contemplating taking a genetic test had to consider the very real possibility that doing so could expose them and even their family members to genetic discrimination—that is, their genetic information could be accessed by third parties, such as insurers and employers, and used against them.<sup>4</sup> Fear of genetic discrimination was prevalent,<sup>5,6</sup> causing many Canadians to decline genetic tests that their physicians believed could benefit their health care.<sup>7</sup>

As committees in the Senate and the House of Commons considered the bill that would become the GNDA, expert witnesses—including some of the authors of this commentary (G.E.G., B.H.M., Y.B.)—shared

stories from Canadians about actual genetic discrimination and fears of genetic discrimination related to a range of genetic mutations associated with various diseases, including breast cancer, hereditary hemochromatosis (HH), cardiomyopathy and other hereditary heart diseases, neurofibromatosis, Lynch syndrome, long QT syndrome, and Huntington disease.<sup>3,8,9</sup> These are described in committee testimony and in speeches throughout the parliamentary record of the legislative history of the GNDA.

On several occasions Dr Ronald Cohn, medical geneticist and President and Chief Executive Officer of the Hospital for Sick Children in Toronto, Ont, told parliamentary committee members about ill children who could not be helped without genetic testing but whose parents, while desperate to help their children, could not consent to genetic testing for fear of genetic discrimination.<sup>7,10,11</sup> In his words:

... [G]enetic discrimination interferes with our ability to provide high-quality, safe, and best-standard clinical care to our patients, something that, in part, can be paralyzing for us as health care providers.<sup>11</sup>

Unlike in many other Western countries,<sup>12</sup> in Canada a person's genetic information was not adequately protected. Our laws had fallen behind the science.

In 2013 Senator James Cowan (J.S.C.) introduced the first version of the bill that would become the GNDA. Despite opposition from the life insurance industry and the federal government, the bill was eventually passed unanimously by the Senate and then was passed by the House of Commons with an overwhelming vote of 222 to 60. It became law on May 4, 2017.<sup>2</sup> Opponents of the law then turned to the courts, alleging the law was unconstitutional—that the matters it covered fell within provincial and territorial jurisdiction and it could not properly be passed by Parliament.

On July 10, 2020, the SCC released its decision on this challenge, holding that the GNDA is constitutional.<sup>1</sup> It has now been settled that the GNDA and its protections of Canadians' genetic test information are valid across Canada.

In the years since the law's passage it has been relied on by countless Canadians in proceeding with genetic testing. We have heard that some wonder whether a future government could repeal the GNDA. While theoretically any law may be repealed, it is highly unlikely in this case, especially as genetic medicine becomes ever more central to high-quality health care. And in the unlikely

case that a future government would attempt to repeal the law, there are legal presumptions to protect anyone who obtained genetic testing while the law was in place.

### What does the GNDA cover?

The law is short at only 3 pages. It applies to everyone in Canada—to all employers, all insurance providers, and all landlords and schools, to name just a few examples. Who you are, or the sector of activity you are engaged in, is irrelevant. The law focuses on the areas of human activity where genetic discrimination is most likely to occur, namely, when someone is providing goods or services to a person or entering into a contract with someone. It sets out 3 prohibitions surrounding genetic testing (**Box 1**).<sup>2</sup>

First, the law prohibits mandatory genetic testing. The provisions of section 3 prohibit any person from requiring someone to take a genetic test as a condition of providing goods or services to that individual, entering into or continuing a contract with that individual, or as a condition of offering or continuing particular terms or conditions in a contract with that person. These provisions also say no one may refuse to provide goods or services, refuse a contract with, or refuse to offer specific conditions to someone because that person has refused to undergo genetic testing.<sup>2</sup>

#### Box 1. Summary of protections under the GNDA<sup>2</sup>

No one providing goods or services to or entering into a contract with someone is permitted to do the following:

- Require that person to take a genetic test
- Require that person to disclose the results of a genetic test
- Collect, use, or disclose that person's genetic test results, no matter how those results were obtained—whether from a family member, a third party, or through trawling the Internet—without the person's written consent

These prohibitions apply to everyone, in all sectors, all across Canada. The only exceptions are for health care practitioners, with respect to individuals to whom they are providing health services, and for persons conducting medical, pharmaceutical, or scientific research, with respect to participants in the research.

Types of test results protected:

- Genetic tests that analyze DNA, RNA, or chromosomes for purposes such as prediction of disease or vertical transmission risks, or for monitoring, diagnosis, or prognosis
- GNDA protections **do not apply** to family history, diagnosis of manifested disease, or symptoms of disease

Criminal penalties apply for breach of any of these prohibitions. Penalties include a fine of up to \$1 million, 5 years imprisonment, or both.

GNDA—Genetic Non-Discrimination Act.

Next, section 4 of the GNDA prohibits mandatory disclosure of genetic test results. It prohibits any person from requiring someone to disclose the results of a genetic test as a condition of engaging in the kinds of activities described above (providing a service, entering into a contract, and so forth). Further, no one may refuse to engage in these activities with someone because that individual refused to disclose the results of a genetic test.<sup>2</sup>

Finally, section 5 of the GNDA prohibits any person who is engaged in the activities at issue (providing a service, etc) from collecting, using, or disclosing someone's genetic test result without that person's written consent. This means that if third parties (such as employers or insurance companies) somehow were to gain access to a person's genetic test result without that person's written consent, they could not use it or tell anyone else about it.<sup>2</sup>

Under this provision, third parties cannot trawl the Internet for mentions of someone's genetic test results—the act of collecting the information is itself a criminal offence. Should a third party learn, for example, that someone had been found to carry a *BRCA1* mutation as a result of a provider-ordered or direct-to-consumer test, they cannot use that information. They are also prohibited from telling anyone about that person's genetic test result.

Even if an individual voluntarily discloses the results of a genetic test to a third party such as an employer or an insurance company, the GNDA prevents the recipient of the information from using it in any manner that has not been consented to in writing. The Act also prevents the recipient from further disclosing the information. Both points were made clear in the SCC's decision (paragraph 54).<sup>1</sup> As the SCC stated:

The most significant practical effect of the Act is that it gives individuals control over the decision of whether to undergo genetic testing and over access to the results of any genetic testing they choose to undergo.<sup>1</sup>

There are 2 exceptions set out in the GNDA. Section 6 of the GNDA states that the prohibitions established in sections 3 to 5 do not apply to a physician, pharmacist, or other health care practitioner with respect to someone to whom they are providing health services. And the law provides an exception for those conducting medical, pharmaceutical, or scientific research with respect to individuals participating in that research.<sup>2</sup> These exceptions ensure that physicians can feel free to recommend genetic tests to their patients and request and receive genetic test information about their patients without fear of violating the prohibitions in the GNDA.

The potential penalties for someone found to have violated the GNDA are substantial—intentionally so, as the law is designed to deter anyone from breaching the Act. Section 7 states that a court may order a fine of up to \$1 million, up to 5 years imprisonment, or both.<sup>2</sup>

There have been suggestions from the insurance industry that provincial legislation might still require individuals to disclose genetic test results as information that is “material to their insurance.”<sup>13</sup> This interpretation is incorrect; in fact, the SCC explicitly anticipated and rejected it. The 2020 decision delivered by Justice Andromache Karakatsanis stated clearly in paragraph 53 that the GNDA would be paramount over provincial provisions to the extent of any conflict:

For instance, provincial legislation that requires an individual seeking health or life insurance to disclose all material health information could not operate so as to require the individual to disclose genetic test results.<sup>1</sup>

It is therefore settled that insurance companies cannot require disclosure of genetic test results, period.

### How is the GNDA relevant to clinical practice?

Most importantly, the GNDA means that physicians can assure their patients that they need not fear genetic discrimination when they decide to take a genetic test. They no longer have to worry that a third party—whether it be a life insurance provider, an employer, a condo board, or anyone else—will be able to access their genetic test results and use them against that person or their family members. Canadians can participate in genetic research studies and clinical trials without fear of being exposed to genetic discrimination.

As a practical matter, the law means that physicians, at a minimum, must exercise care when sharing patients’ medical information with third parties (such as life insurance providers) to ensure that any genetic test results are not included in the patient’s file. This requires removing not only the actual genetic test report but all references to any genetic test result in a patient’s file.

Nothing in the Act prevents individuals from voluntarily sharing their own genetic test results with a third party. But no third party may demand the information. For example, an employee might choose to share her genetic test information with her employer, but the employer may not demand the information as a condition of employment or promotion. Similarly, individuals might choose to share genetic test results with insurance providers, and in that case might be offered and receive lowered premiums. But no insurance provider may request the information, nor may it require the test results as a condition of offering certain terms, such as lower premiums. And the fact that an individual chose to share the information does not mean that the recipient, for example, an employer or insurance company, has been authorized to use or share the information in any manner that has not been consented to by the individual in writing.

The law focuses only on genetic tests. Family medical history and the person’s own medical history are not affected by the law. If a person has actually developed a

disease or condition, that fact is as disclosable as it was before the GNDA.

It is important to distinguish between a genetic test result and an actual diagnosis of an existing disease. The former is private and not to be shared with third parties; the latter is not covered by the GNDA.

Similarly, clinicians will need to distinguish between documentation of risk versus existing disease.

For example, HH is the most common autosomal recessive predisposition in North American individuals of northern European ancestry. One in 300 North Americans of this descent have inherited 2 altered copies of the hemochromatosis (*HFE*) gene, increasing their risk of developing iron overload.<sup>14</sup> If a person knows they carry 2 altered copies of the *HFE* gene, there are simple steps they can take—lifestyle adjustments to minimize their risk and routine iron monitoring through their physician—that will prevent symptoms from developing. If a person has developed symptoms that led to a clinical diagnosis of HH, that fact is disclosable, as is any family history of HH, as it was before the GNDA became the law.

An individual who is determined by genetic testing to carry the predisposing genotype for hemochromatosis but who does not have iron overload by standard biochemical testing is not *affected with* HH. And, in all cases, the person’s genetic test results are private and not to be shared.

Whether a patient has developed a particular disease is a matter for the physician to determine. But under the GNDA, the genetic test result is protected information, personal to the patient.


In section 2, the GNDA defines a genetic test to mean “a test that analyzes DNA, RNA or chromosomes for purposes such as the prediction of disease or vertical transmission risks, or monitoring, diagnosis or prognosis.”<sup>2</sup> Thus, genetic tests conducted for diagnostic purposes are protected, as are those conducted for predicting possible future disease risk.

### Conclusion

The protection against genetic discrimination provided by the GNDA is among the strongest in the world. Most countries approach the issue on a sector-by-sector basis, such as prohibiting use of genetic information by employers or the insurance industry. That approach has often left gaps and presented problems as genetic discrimination arose in new sectors. For example, the US Genetic Information Nondiscrimination Act of 2008 addresses employers and health insurance but notably does not apply to the life insurance industry.<sup>15</sup> And genetic discrimination has since arisen elsewhere, such as in schools and via condo boards, which fall outside US federal law.

The GNDA applies to everyone, in all sectors, across Canada. Who someone is or what business they are in is irrelevant. What matters is their conduct. No one providing a good or service or entering into a contract can require someone to take a genetic test; require someone

to disclose the results of a genetic test; or collect, use, or disclose someone's genetic test results without that person's written consent.

The GNDA marks a milestone in protecting Canadians' genetic information. It clears the way for Canadians who choose to have genetic testing, either for the purpose of their own care or to participate in research, without fear that they or their families could be exposed to genetic discrimination. They will be able to benefit from and contribute to the extraordinary advances taking place in genetic science and medicine. 

**James S. Cowan** is a retired Senator of the Senate of Canada. **Barbara Laine Kagedan** is a retired Director of Policy to Senator Cowan. **Dr Gail E. Graham** is retired Chief of the Department of Genetics at the Children's Hospital of Eastern Ontario in Ottawa. **Bev Heim-Myers** is Past Chief Executive Officer of the Huntington Society of Canada and Chair of the Canadian Coalition for Genetic Fairness in Waterloo, Ont. **Dr Yvonne Bombard** is Associate Professor in the Institute of Health Policy, Management and Evaluation at the University of Toronto in Ontario and Scientist at the Li Ka Shing Knowledge Institute of St Michael's Hospital Unity Health Toronto.

#### Competing interests

None declared

#### Correspondence

**Dr Yvonne Bombard**; e-mail [yvonne.bombard@utoronto.ca](mailto:yvonne.bombard@utoronto.ca)

The opinions expressed in commentaries are those of the authors. Publication does not imply endorsement by the College of Family Physicians of Canada.

#### References

1. Reference re Genetic Non-Discrimination Act, 2020 SCC 17. Ottawa, ON: Supreme Court of Canada; 2020. Available from: <https://www.canlii.org/en/ca/scc/doc/2020/2020scc17/2020scc17.html>. Accessed 2020 Dec 2.
2. Genetic Non-Discrimination Act, SC 2017, c 3. Ottawa, ON: Department of Justice; 2017. Available from: <https://laws-lois.justice.gc.ca/PDF/G-2.5.pdf>. Accessed 2020 Dec 2.
3. Evidence: Bill S-201, an Act to prohibit and prevent genetic discrimination. 42nd Parliament, 1st Sess., meeting no. 37. Ottawa, ON: House of Commons Standing Committee on Justice and Human Rights; 2016. Available from: <https://www.ourcommons.ca/DocumentViewer/en/42-1/just/meeting-37/evidence>. Accessed 2022 Jul 23.
4. Bombard Y, Heim-Myers B. The Genetic Non-Discrimination Act: critical for promoting health and science in Canada. *CMAJ* 2018;190(19):E579-80.
5. Bombard Y, Palin J, Friedman JM, Veenstra G, Creighton S, Botorff JL, et al. Beyond the patient: the broader impact of genetic discrimination among individuals at risk of Huntington disease. *Am J Med Genet B Neuropsychiatr Genet* 2012;159B(2):217-26. Epub 2012 Jan 9.
6. Bombard Y, Veenstra G, Friedman JM, Creighton S, Currie L, Paulsen JS, et al. Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey. *BMJ* 2009;338:b2175.
7. Evidence: Bill S-201, an Act to prohibit and prevent genetic discrimination. 41st Parliament, 2nd Sess., issue 11. Ottawa, ON: Standing Senate Committee on Human Rights; 2014. Available from: <https://sencanada.ca/en/Content/SEN/Committee/412/ridr/11ev-51620-e>. Accessed 2022 Jul 23.
8. Evidence: Bill S-201, an Act to prohibit and prevent genetic discrimination, before the Standing Committee on Justice and Human Rights. 42nd Parliament, 1st Sess., meeting no. 35. Ottawa, ON: House of Commons Standing Committee on Justice and Human Rights; 2016. Available from: <https://www.ourcommons.ca/DocumentViewer/en/42-1/JUST/meeting-35/evidence>. Accessed 2022 Aug 8.
9. Bombard Y. Written testimony to the Standing Senate Committee on Human Rights regarding Bill S-201, an Act to prohibit and prevent genetic discrimination. Ottawa, ON: House of Commons Standing Committee on Human Rights; 2014. Available from: [https://sencanada.ca/content/sen/committee/421/RIDR/Briefs/Bombard-UnivTorontoWrittenTestimony\\_e.pdf](https://sencanada.ca/content/sen/committee/421/RIDR/Briefs/Bombard-UnivTorontoWrittenTestimony_e.pdf). Accessed 2022 Aug 8.
10. Evidence: Bill S-201, an Act to prohibit and prevent genetic discrimination. 42nd Parliament, 1st Sess., issue 2. Ottawa, ON: Standing Senate Committee on Human Rights; 2016. Available from: <https://sencanada.ca/en/Content/SEN/Committee/421/ridr/02ev-52394-e>. Accessed 2022 Jul 23.
11. Evidence: Bill S-201, an Act to prohibit and prevent genetic discrimination. 42nd Parliament, 1st Sess., meeting no. 36. Ottawa, ON: Standing Senate Committee on Human Rights; 2016. Available from: <https://www.ourcommons.ca/DocumentViewer/en/42-1/JUST/meeting-36/evidence>. Accessed 2022 Jul 24.
12. Otlowski M, Taylor S, Bombard Y. Genetic discrimination: international perspectives. *Annu Rev Genomics Hum Genet* 2012;13:433-54. Epub 2012 May 15.
13. Bienenstock Y, Bernstein A, Richter C. Genetic discrimination: it's criminal! [blog]. *Torys*; 2020 Jul 14. Available from: <https://www.torys.com/Our%20Latest%20Thinking/Publications//2020/07/genetic-discrimination/>. Accessed 2022 Aug 8.
14. Adams PC, Reboussin DM, Barton JC, McLaren CE, Eckfeldt JH, McLaren GD, et al. Hemochromatosis and iron-overload screening in a racially diverse population. *N Engl J Med* 2005;352(17):1769-78.
15. Genetic information nondiscrimination act of 2008. 110th Cong. 2008. Pub L No 110-233. 122 Stat 881. Available from: <https://www.govinfo.gov/content/pkg/PLAW-110publ233/pdf/PLAW-110publ233.pdf>. Accessed 2020 Dec 2.

This article has been peer reviewed.

*Can Fam Physician* 2022;68:643-6. DOI: 10.46747/cfp.6809643

La traduction en français de cet article se trouve à <https://www.cfp.ca> dans la table des matières du numéro de septembre 2022 à la page e252.