

Genetic Discrimination and the Workplace: An Update on the Evolving Legal Landscape

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Introduction

Genetic characteristics are the hereditary traits of an individual that may include the inheritance of disorders or predispositions towards diseases. Genetic testing has become increasingly prevalent in the past few years primarily due to consumer-oriented services such as 23andMe and AncestryDNA which can be used to trace one's family ancestry. Heightened social awareness around health and fitness has also created a greater consciousness around the role genetics play in numerous medical concerns.

The prevalence of genetic information has created a corresponding fear of genetic discrimination. Genetic discrimination involves unfair treatment because of perceived risks around an individual's predisposition towards inherited illnesses.

In response to growing concerns, the federal *Genetic Non-Discrimination Act* was enacted on May 4th, 2017.¹ The legislation enacts a number of protections for individuals who undergo genetic tests, and amends the *Canada Labour Code* to prevent employers from requiring genetic tests or requiring the disclosure of genetic test results from federal employees.² The *GND*A also amends the *Canadian Human Rights Act* to add "genetic characteristics" as a prohibited ground of discrimination.³

In terms of Ontario law, Bill 40, *Human Rights Code Amendment Act (Genetic Characteristics)*, 2018 is a proposed statute that seeks to amend the *Human Rights Code* to include genetic characteristics as a prohibited ground of discrimination.⁴ The bill has currently been referred to a Standing Committee on the Legislative Assembly.

The purpose of this paper is to (1) provide a background on genetic testing and discrimination; (2) explore the legislative initiatives taken to address genetic discrimination; (3) opine on the scope of protection offered by legislative initiatives and case law, and (4) conclude with a discussion on the intersection between genetic discrimination, insurance and workplaces.

Background

What is Genetic Testing?

Genetic tests analyze an individual's DNA to identify specific traits or markers which are indicative of heredity or vulnerability to inherited conditions. Tests can assist in ascertaining a person's likelihood of developing an illness and they can confirm or exclude the presence of markers suggestive of disease.

¹ *Genetic Non-Discrimination Act*, SC 2017, c 3 [GND]A].

² *Canada Labour Code*, RSC, 1985, c L-2 [CLC].

³ *Canadian Human Rights Act*, RSC, 1985, c H-6 [CHRA].

⁴ 1st Sess, 42nd Leg, Ontario, 2018 [Bill 40].

It is important to remember that a genetic test itself is not inherently negative and can, in fact, provide a myriad of benefits to a person seeking information. For instance, having access to a patient's genetic profile can assist medical professionals in diagnosing and refining treatments of disease that can be more attuned to the patient's needs. This is why genetic testing is often referred to as "personalized medicine" or "individualized medicine".⁵ Broadly, genomic technologies have the potential to more effectively predict or detect illnesses and can prompt early monitoring and prevention measures. The timely discovery and treatment of different conditions can provide immense advantages to health-conscious individuals.

However, genetic tests currently have notable drawbacks in their reliability. While identifying genetic anomalies can sometimes be used to assess the likelihood of developing future illnesses, genetic tests do not provide absolute certainty. If an individual tests positive for genetic anomalies or carries DNA that pre-disposes them to certain conditions, it does not mean that those anomalies or conditions will manifest into physical disorders or diseases.⁶ This is because personal health is the result of a complex intermingling of heredity, lifestyle, environmental factors that makes it nearly impossible for tests to provide any significant degree of certainty.

What is Genetic Discrimination?

Along with the prevalence of testing is an apprehension around the use of genetic information to discriminate against individuals. For instance, employees could hypothetically face reprisals if they decline genetic testing or if they decline to disclose test results. Alternatively, employers could hypothetically require candidates to undergo genetic testing as a qualification of employment and refuse to hire individuals based on their chances of encountering genetic health risks. Employers could theoretically use genetic screening of this nature to reduce their likelihood of encountering workplace disability or accommodation situations.

Conversely, employers may manipulate genetic information to screen for attributes they consider to be "positives". For example, a theoretical scenario could involve employers in physically demanding fields who administer genetic tests to select applicants with a reduced need for sleep or a high tolerance for physical stress. In that scenario, applicants would be discriminated against if they did not express the desired hereditary traits.

While many of these concerns are largely speculative for the moment, genetic screening can be used in a myriad of ways to differentiate amongst individuals in the absence of a regulatory framework. This may also have a "chilling effect" where individuals abstain from genetic testing out of fear that the information can adversely be

⁵ Senate of Canada, Proceedings of the Standing Senate Committee on Human Rights, *Evidence*, 42-1, No 2 (24 February 2016) (Stephen Scherer).

⁶ Canadian Cancer Society, "Genetic testing", online: *Canadian Cancer Society* <<https://www.cancer.ca/en/cancer-information/cancer-101/what-is-cancer/genes-and-cancer/genetic-testing/?region=on>>.

used to prejudice them.

Legislative Changes: An Overview

Federal Legislation

Genetic Non-Discrimination Act

The *GND*A is Canada's first anti-genetic discrimination statute. It prohibits any person from requiring genetic test results when providing goods or services, entering contractual agreements or offering specific terms or conditions in a contract:⁷

Genetic test

3 (1) It is prohibited for any person to require an individual to undergo a genetic test as a condition of

- (a) providing goods or services to that individual;
- (b) entering into or continuing a contract or agreement with that individual; or
- (c) offering or continuing specific terms or conditions in a contract or agreement with that individual.

Refusal to undergo genetic test

(2) It is prohibited for any person to refuse to engage in an activity described in any of paragraphs (1)(a) to (c) in respect of an individual on the grounds that the individual has refused to undergo a genetic test.

Disclosure of results

4 (1) It is prohibited for any person to require an individual to disclose the results of a genetic test as a condition of engaging in an activity described in any of paragraphs 3(1)(a) to (c).

Refusal to disclose results

(2) It is prohibited for any person to refuse to engage in an activity described in any of paragraphs 3(1)(a) to (c) in respect of an individual on the grounds that the individual has refused to disclose the results of a genetic test.

⁷ *Supra* note 1 at s. 3.

The Act does not restrict its scope to a federal jurisdiction, making it applicable to all persons and businesses, provincial or otherwise.⁸ Contravention of the Act is punishable as a criminal offence. An indictable offence is punishable by a \$1,000,000 fine and/or up to five years of imprisonment. A summary conviction is punishable by a \$300,000 fine and/or up to a year of imprisonment.⁹ Exceptions are provided to medical professionals such as physicians or pharmacists as well as pharmaceutical or scientific researchers.¹⁰

Since the *GND*A's prohibitions are directed to "any person" and insurance is not mentioned as an exclusion in the Act, insurance companies are likely caught by the statute's wording. Thus, the *GND*A's broad prohibitions should make it illegal for insurers to collect, use or disclose genetic data as a condition of insurance.¹¹ Prior to the *GND*A's enactment, the Canadian Life and Health Insurance Association entered into a voluntary code to not demand genetic tests for new policies valued at less than \$250,000.¹²

The Senate of Canada contemplated a constitutional challenge against the Act during its debate sessions. Professor Bruce Ryder of Osgoode Hall and Professor Pierre Thibault of Ottawa Faculty of Law were consulted as to the *GND*A's constitutionality and opined "unequivocally" that the bill was a constitutionally valid exercise of federal legislative jurisdiction.¹³ Senator James Cowan commented that:

This is not targeting any particular industry or any particular transaction, but it is intended to target behaviour that is prohibited. The legal constitutional scholars I've spoken to believe that as long as the prohibition is general in nature, is not targeting any particular industry or person and is of application to anyone who carries out a prohibited activity, it is a legitimate use of the federal power to legislate for criminal law.¹⁴

The Senate also contemplated whether the Act was a valid exercise of criminal law power. Member of Parliament Alistair MacGregor cited the Supreme Court of Canada's ("**SCC**") analysis in the *Reference re Assisted Human Reproduction Act* where it was

⁸ Canadian Civil Liberties Association, "The Genetic Non-Discrimination Act – An Overview" (11 April 2018), online: Canadian Civil Liberties Association <<https://ccla.org/genetic-non-discrimination-act-overview/>>

⁹ *Supra* note 1 at s. 7.

¹⁰ *Ibid* at s. 6.

¹¹ *Supra* note 1 at s. 5.

¹² *Supra* note 18; The Canadian Press, "Canadian life insurers to limit use of genetic test results" (11 January 2017), online: *CBC* <<https://www.cbc.ca/news/business/canada-life-insurance-genetic-testing-1.3930664>>.

¹³ "S-201, An Act to prohibit and prevent genetic discrimination" Second Report of Human Rights Committee - Debate Adjourned, *Senate of Canada Debates*, 42-1, No 11 (22 March 2016) at 1440 (Hon James Cowan).

¹⁴ "S-201, An Act to prohibit and prevent genetic discrimination" 2nd Reading, *Senate of Canada Debates*, 42-1, No 8 (27 January 2016) at 1500 (Hon James Cowan).

held that “acts or conduct that have an injurious or undesirable effect on public health constitute public health evils that may properly be targeted by the criminal law”.¹⁵

During debates, Senator Cowan offered testimony about Canadians who chose not to pursue preventative genetic testing due to the lack of certainty around how the information could be used against them. For instance, one story involved parents with sick children who required genetic testing. The parents were highly reluctant to engage with the testing out of fear that it would negatively affect their insurability.¹⁶

Using that testimony and the SCC’s reasoning, MP MacGregor characterized genetic discrimination as a public health evil in need of clear legal protections:

Discrimination based on genetic testing does have an injurious and undesirable effect on public health. When people are too afraid to go for genetic testing because of the fears of discrimination, this does not allow physicians to do their job properly. Taking a test that could help someone’s life should not be a calculated risk.

Following its enactment, the Quebec government challenged the *GND*A’s constitutionality on the grounds that it was *ultra vires* the Canadian government. The provisions amending the *Canadian Human Rights Act* and the *Canada Labour Code* were not challenged since they clearly fell within federal jurisdiction. Interestingly, the federal government did not defend the law. An *amicus curiae* was appointed and interveners stepped forward to support the Act.¹⁷

The five-judge panel of the Quebec Court of Appeal struck down the law as unconstitutional on December 21st, 2018.¹⁸ The Court reasoned that there was a difference between protecting a community from a dangerous health risk versus promoting positive health.¹⁹ Based on that logic, the Court found that the *GND*A’s pith and substance was to promote the medical health of Canadians by emboldening access to genetic tests.²⁰ The *GND*A does this specifically through mitigating social fear that genetic information could disadvantageously be used against the test-taker. Consequently, there was no legitimate criminal law purpose since motivating the usage of genetic tests was not a “real public health evil”:

There is no “real public health evil” here that would justify the recourse to subsection 91(27) of the *Constitution Act, 1867*. The criminal law object advanced to justify the Act is to provide higher quality health care through the

¹⁵ *Reference re Assisted Human Reproduction Act*, 2010 SCC 61 at para 62.

¹⁶ *Supra* note 24 at 1440.

¹⁷ Mathieu Gagné, Dara Jospé and Michael Shortt, “Québec Court of Appeal Strikes Down Federal Genetic Non-Discrimination Act” (24 January 2019), online: *Fasken* <<https://www.fasken.com/en/knowledge/2019/01/quebec-court-of-appeal-strikes-down-federal-genetic-non-discrimination-act/>>.

¹⁸ *Reference Re Genetic Non-Discrimination Act*, 2018 QCCA 2193.

¹⁹ *Ibid* at para 24.

²⁰ *Ibid* at para 8.

promotion of access to genetic tests by suppressing the fear that the results of these tests be used for insurance or employment purposes. This is clearly not a criminal law object. The situation is completely distinguishable from the exercise of federal jurisdiction over criminal law regarding tobacco or illicit drugs, which intrinsically present a threat to public health. That is not the case for genetic tests.²¹

On January 16th, 2019, the Canadian Coalition of Genetic Fairness filed a notice of appeal to the SCC pursuant to s. 36 of the *Supreme Court Act*.²² The Coalition was an intervening party in the Quebec case. The appeal is as of right and will eventually be decided by the SCC.²³ One of the main questions presented in the appeal is whether the *GND* is focused on a “real public health evil”. If the Quebec Court of Appeal’s decision is affirmed then legislative protections against genetic discrimination will likely be delegated to individual provinces. If the decision is overturned, the Act will remain in force and the federal government will have the authority to broadly regulate against genetic discrimination so long as there is no overt intrusion upon provincial jurisdiction. For the time being, the *GND*’s disputed sections remain in force and individuals remain subject to the Act’s sanctions.²⁴

The *GND* amended the *Canadian Human Rights Act* and *Canada Labour Code*. These amendments are still in force and are discussed below.

Canadian Human Rights Act

The *CHRA* is federal legislation that prohibits discriminatory practices against individuals in federally-regulated activities. Genetic characteristics are an enumerated ground of discrimination under subsection 3(1). Subsection 3(3) of the *CHRA* also prohibits discrimination against individuals who refuse genetic testing or individuals who refuse to disclose genetic test information. The *CHRA* does not contain definitions of “genetic test” or “genetic characteristics”, leaving it to the judiciary to interpret the scope of those terms.

The *CHRA* only applies to individuals in areas of federal jurisdiction, such as federally-regulated employers and federally-regulated service providers. Federally-regulated industries include:

- Air transportation, including airports, aerodromes and airlines
- Banks
- Businesses dealing with the protection of fisheries as a natural resource
- Canals, pipelines, tunnels and bridges (crossing provincial borders)

²¹ *Ibid* at para 24.

²² *Supra* note 27.

²³ *Ibid*.

²⁴ Nathalie David & Thomas Perrino, “The *Genetic Non-Discrimination Act*: still in force, but uncertainty remains” (24 April 2019), online: *Clyde & Co.* <<https://www.clydeco.com/insight/article/the-genetic-non-discrimination-act-still-in-force-but-uncertainty-remains>>.

- Grain elevators, feed and seed mills
- Many first nation activities
- Marine shipping, ferry and port services
- Most federal crown corporations
- Private businesses necessary to the operation of a federal act
- Radio and television broadcasting
- Railway and road transportation that involves crossing provincial or international borders
- Telephone, telegraph and cable systems
- Uranium mining and processing²⁵

Canada Labour Code

The *CLC* is federal legislation that regulates the labour and employment rights of federal employees. The *CLC*'s language is far more expansive than the *CHRA* regarding protection against genetic discrimination. Section 247.98 of the *CLC* entitles employees to refuse genetic testing and to refuse the disclosure of genetic test results. Subsection 247.98(4) of the *CLC* prohibits employers from penalizing employees who refuse genetic testing or employees who refuse to disclose genetic test information. If an adjudicator determines that an employer has contravened s. 247.98, they may order the employer to reinstate the employee, compensate the employee, rescind disciplinary actions, or apply other equitable remedies to the circumstances.

The *CLC* only applies to employees in areas of federal jurisdiction, such as federally-regulated employers and federally-regulated service providers. Employees who are not employed in federally-regulated industries are outside the scope of the *CLC*.

Ontario Legislation

Bill 40 was introduced in the Ontario Legislature on October 3rd, 2018 by Member of Provincial Parliament Christina Mitas as a private member's bill. The bill has passed its second reading and was referred to a Standing Committee of the Legislative Assembly on October 18th, 2018. Bill 40 would come into force on the day it receives Royal Assent if it is successfully passed.²⁶

Ontario has introduced legislation to prohibit genetic discrimination before. Bill 164 was introduced on October 4th, 2017 and would have amended the *Human Rights Code* to include genetic characteristics as a protected ground. The bill died on Order Paper when Ontario's 41st parliamentary session ended prior to the 2018 provincial election.²⁷

²⁵ Government of Canada, "Employment standards" (Jan 2019), online: *Government of Canada* <<https://canadabusiness.ca/government/regulations/regulated-business-activities/human-resources-regulations/employment-standards/>>.

²⁶ *Supra* note 4 at s. 9.

²⁷ Alexander Dezan, "Ontario election expected to determine survival of *Human Rights Code* amendments" (22 May 2018), online: *Ottawa Business Journal* <<https://obj.ca/article/ontario-election-expected-determine-survival-human-rights-code-amendments>>.

Bill 164 was reintroduced on September 26th, 2018 as Bill 35 but it did not advanced past its first reading.²⁸

Bill 40 aims to amend Ontario's *Human Rights Code* by prohibiting discrimination based on "genetic characteristics" with respect to employment, goods and facilities, membership in various organizations, the occupancy of accommodation, and contracts and services. "Genetic characteristics" is defined as "genetic traits of an individual, including traits that may cause or increase the risk to develop a disorder or disease".²⁹ Every person would be guaranteed the right to equal treatment should they refuse genetic testing or refuse the disclosure of genetic test information.³⁰

Much like the *GND*, Bill 40 was conceptualized with an altruistic intent – namely to remove the fear surrounding access to genetic data. During debates, MPP Mitas used the example of breast cancer to illustrate this intent. The Canadian Cancer Society estimates that one out of every eight women will develop breast cancer in their lifetimes but women who carry a BRCA gene mutation carry a notably higher chance of manifesting breast cancer.³¹ Possession of this knowledge can allow one to assess their options, prepare for treatment and modify their healthcare in a manner that benefits their genetic circumstances.

Bill 40 is not all positive, however. The proposed legislation contains exemptions for insurers who would be permitted to differentiate, make distinctions, exclude, or prefer individuals based on genetic characteristics where there are reasonable and *bona fide* grounds.³² This exemption applies to insurance contracts for automobiles, life, accident or sickness, disability, group insurance between an insurer and an association or person other than an employer, or a life annuity. The likely rationale for this is due to genetic characteristics being materially relevant information that would affect the insurer's acceptance of risk and the value of insurance policies or coverage.

Dispute over the exemption for insurers arose during the bill's debates. Despite authoring the exemption, MPP Mitas relayed a story about an 18-year-old woman who tested positive for a BRCA gene. Her insurer cancelled her policy although she eventually requalified for limited coverage. The test results also affected the woman's family who statistically had a 50% chance of carrying the BRCA gene. Consequently, neither her mother nor her aunt applied for insurance and her brother refused testing.³³

MPP Suze Morrison further criticized the exclusion of insurers from the bill's scope, asking: "What good are human rights if we're only willing to expand them in theory but

²⁸ Legislative Assembly of Ontario, "Status – Bill 35, *Human Rights Code Amendment Act, 2018*", online: *Legislative Assembly of Ontario* <<https://www.ola.org/en/legislative-business/bills/parliament-42/session-1/bill-35/status>>.

²⁹ *Supra* note 4 s. 6(1).

³⁰ *Ibid* at s. 6(2).

³¹ "Bill 40, *Human Rights Code Amendment Act (Genetic Characteristics), 2018*", *House of Commons Debates*, 42-1 (18 October 2018) at 1430 (Christina Mitas).

³² *Supra* note 4 at s. 7.

³³ *Supra* note 12 at 1440.

not in a meaningful way that effects lasting and effective change?”³⁴ In response, MPP Mitas ultimately affirmed that she was seeking to strengthen the language of the bill.³⁵

International Legislation

Canada is a relative latecomer in establishing a genetic regulatory system, for many years being the only G7 country without an anti-genetic discrimination regime.³⁶ Many countries within Europe as well as the United States have already adopted legislation to protect their citizens against the misuse of genetic information. Below are some examples of how genetic discrimination is addressed in other countries.

United Nations

In 1997, the United Nations Educational, Scientific and Cultural Organization (“UNESCO”) adopted the “Universal Declaration on the Human Genome and Human Rights”.³⁷ The declaration is intended to prevent genetic discrimination by characterizing it as an affront to widely-held human rights principles:

Article 6

No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

UNESCO further adopted the “International Declaration on Human Genetic Data” in 2003.³⁸ The declaration establishes ethical principles to govern the use of genetic characteristics. Genetic data is again affirmed as a prohibited ground of discrimination:

Article 7 – Non-discrimination and non-stigmatization

(a) Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that lead to the stigmatization of an individual, a family, a group or communities.

³⁴ *Ibid* at 1500 (Suze Morrison).

³⁵ *Ibid* at 1510 (Christina Mitas).

³⁶ Kerry Gold, “How genetic testing can be used against you – and how Bill S-201 could change that” (3 April 2016), online: *The Globe and Mail* <[³⁷ \(11 Nov 1997\), online: *United Nations Educational, Scientific and Cultural Organization* <\[>\]\(http://portal.unesco.org/en/ev.php-URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html\).](https://beta.theglobeandmail.com/life/health-and-fitness/health/bill-s-201-aims-to-end-genetic-discrimination-in-canada/article29494782/?ref=http://www.theglobeandmail.com&.>.</p></div><div data-bbox=)

³⁸ (16 Oct 2003), online: *United Nations Educational, Scientific and Cultural Organization* <[>](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=DO_TOPIC&URL_SECTION=201.html).

United States of America

The *Genetic Information Nondiscrimination Act* is a federal statute that was enacted on May 21st, 2008.³⁹ *GINA* covers genetic testing in the areas of employment and health insurance, but does not extend to other forms of insurance such as life, disability or long-term care. “Genetic information” is defined as:

- (i) such individual’s genetic tests,
- (ii) the genetic tests of family members of such individual, and
- (iii) the manifestation of a disease or disorder in family members of such individual.⁴⁰

GINA applies to all private US employers with 15 or more employees in addition to all federal and state government employers.⁴¹ The statute prevents employers, employment agencies, labour groups, joint labour-management training programs, and apprenticeship programs from discriminating against individuals because of genetic information. Discrimination includes hiring, firing, assigning, or promoting based on genetic characteristics.⁴² *GINA* prohibits employers from requesting or requiring genetic information as a condition of employment.⁴³

GINA contains some exceptions to the prohibition against employers acquiring genetic information. For example, genetic information can be acquired if it is used to monitor the biological effects of toxic substances in the workplace.⁴⁴ Another example is when an employer requires family medical history to comply with requirements under the *Family and Medical Leave Act*.⁴⁵ Despite these exceptions, employers are still forbidden from utilizing genetic characteristics for employment decisions and must maintain any genetic information in confidence.⁴⁶

GINA also bars health insurers from determining health insurance eligibility, coverage, underwriting, or premiums on the basis of genetic traits.⁴⁷ As a result, insurers cannot deny coverage or charge higher premiums for health insurance based solely on genetic predispositions towards diseases or illnesses. As mentioned, however, these protections do not apply to insurance for life, disability, and long-term care.

³⁹ Pub L 110–233, 122 Stat 881, enacted May 21, 2008 [*GINA*].

⁴⁰ *Ibid* at s. 201(4)(A).

⁴¹ US Equal Employment Opportunities Commission, “Facts About the Genetic Information Nondiscrimination Act”, online: *US Equal Employment Opportunities Commission* <<https://www.eeoc.gov/eeoc/publications/fs-gina.cfm>>.

⁴² *Supra* note 39 at s 202(a).

⁴³ *Ibid* at s. 202(b).

⁴⁴ *Ibid* at s. 202(b)(5).

⁴⁵ *Ibid* at s. 202(b)(3).

⁴⁶ *Ibid* at s. 202(b).

⁴⁷ *Ibid* at s. 101(c)(1)(C).

In 2017, the Republican-controlled U.S. Congress introduced a bill to amend *GINA* to allow employers to demand the results of any genetic test that an employee may take.⁴⁸ Its passage is highly unlikely as the bill failed to advance to the U.S. Senate before the 2018 midterms, however.

United Kingdom

The United Kingdom has abstained from legislating genetic discrimination. In 2007, the UK government declined adding genetic characteristics as a protected ground under their anti-discrimination laws.⁴⁹ Instead, employers and insurers must comply with the *Data Protection Act, 2018* which outlines privacy rights regarding the use of personal information.⁵⁰ Section 205 of the *DPA* contains its own definition of “genetic data”:

205 General interpretation

“genetic data” means personal data relating to the inherited or acquired genetic characteristics of an individual which gives unique information about the physiology or the health of that individual and which results, in particular, from an analysis of a biological sample from the individual in question

While no UK legislation bans the use of genetic information in insurance, the United Kingdom government and the Association of British Insurers entered into a moratorium from 2014 to 2019 which voluntarily forbids the use of genetic traits in insurance underwriting.⁵¹ There are some exceptions, such as life insurance policies over £500,000, critical illness policies over £300,000 or income protection policies that pay annual benefits over £30,000.⁵² In those situations, insurers can seek information about genetic traits and customers must disclose the results of genetic tests.⁵³

France

France does not have a central genetic discrimination statute but has several provisions within different statutes that set out principles against genetic discrimination. For instance, France’s *Code pénal* (English: *Penal Code*) mandates that if genetic data is obtained for medical or scientific purposes and improperly exploited then it is punishable with one year of imprisonment and a €15,000 fine.⁵⁴

⁴⁸ H.R. 1313, “Preserving Employee Wellness Programs Act”.

⁴⁹ Julian Walker, “Genetic Discrimination and Canadian Law” (16 Sept 2014), online: *Parliament of Canada* <https://lop.parl.ca/sites/PublicWebsite/default/en_CA/ResearchPublications/201490E>.

⁵⁰ (UK), Queen Elizabeth II [*DPA*].

⁵¹ HM Government & Association of British Insurers, “Concordat and Moratorium on Genetics and Insurance” (2014), online: *Association of British Insurers* <<https://www.abi.org.uk/globalassets/sitecore/files/documents/publications/public/2014/genetics/concordat-and-moratorium-on-genetics-and-insurance.pdf>>.

⁵² *Ibid* at s. 26(i).

⁵³ *Ibid* at s. 26(ii).

⁵⁴ JO, March 1, 1994 (France) at Article 226-25.

Article L1132-1 of France's *Code du travail* (English: *Labour Code*) outlines genetic characteristics as a prohibited ground of discrimination in employment:

Article L1132-1

No person may be excluded from a recruitment procedure or from access to an internship or a period of training in a company, no employee may be sanctioned, dismissed or subject to a discriminatory measure, direct or indirect. indirect rule , as defined in Article 1 of Law No 2008-496 of 27 May 2008 laying down various provisions for adapting to Community law in the field of combating discrimination, in particular as regards remuneration, within the meaning of Article L. 3221-3, incentive measures or share distribution, training, reclassification, assignment, qualification, classification, professional promotion, transfer or renewal of contract because of... his genetic characteristics.

This language represents a very thorough approach towards ensuring that genetic traits cannot form the basis of recruitment and employment decisions.

Case Law: An Overview

There have been no cases that directly address genetic discrimination in Canada. However, the 2000 SCC case of *Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City); Quebec (Commission des droits de la personne et des droits de la jeunesse) v Boisbriand (City)* contemplates disability discrimination in a manner that may influence potential genetic discrimination cases.⁵⁵ In that case, the SCC held that a handicap is not limited to a physical medical condition but can constitute an individual's perceived medical limitation.⁵⁶

The decision arose from two separate handicap discrimination claims under Quebec's *Charter of Human Rights and Freedoms*.⁵⁷ One claim involved two individuals who were denied employment with the city of Montreal due to spinal anomalies revealed in a medical exam. The other claim involved an individual who was dismissed from employment with the city of Boisbriand after missing work due to a complication involving Crohn's disease. Despite that, the perceived conditions had not manifested into actual physical limitations that would impede the individuals' performance of their job responsibilities.

In both cases, the employers argued that the perceived medical conditions would be too costly to accommodate and would interfere with long-term employment duties.⁵⁸ The employers also argued that the individuals were not covered by the Quebec *Charter's*

⁵⁵ *Quebec (Commission des droits de la personne et des droits de la jeunesse) v Montréal (City); Quebec (Commission des droits de la personne et des droits de la jeunesse) v Boisbriand (City)*, 2000 SCC 27 [Boisbriand].

⁵⁶ *Ibid* at para 81.

⁵⁷ CQLR, c. C-12 at s. 10 [Quebec *Charter*].

⁵⁸ *Supra* note 54 at para 3.

handicap provision because the provision only related to discrimination based on actual functional limitations. They contended that the individuals' medical limitations were merely perceived and therefore did not fall into the definition of "handicap".⁵⁹

The SCC found that discrimination had taken place contrary to Quebec's *Charter*.⁶⁰ While Quebec's *Charter* did not define "handicap", L'Heureux-Dubé J. noted that there is a strong subjective component to handicaps, meaning that a handicap can be based in stereotypes without explicit proof.⁶¹ In this case, the refusal to hire and the dismissal from employment were causally connected to the employers' perception of the individuals' medical disadvantages.⁶² The SCC consequently held that the three individuals were discriminated against on the basis of handicap.⁶³

Although this case did not specifically address genetic discrimination, L'Heureux-Dubé J. expressly referenced the changing nature of genetic technology in applying a broad handicap definition:

Given both the rapid advances in biomedical technology, and more specifically in genetics, as well as the fact that what is a handicap today may or may not be one tomorrow, an overly narrow definition would not necessarily serve the purpose of the *Charter* in this regard.⁶⁴

This statement illustrates that legal comprehensions of disability are not static but are instead capable of evolving as society evolves. Genetic discrimination may consequently come to be articulated through the language of disability due to the comparable presence of perception-based stereotyping.

The medical conditions dealt with in this case have a great resemblance to the genetic predispositions contemplated by the *CHRA*, *CLC* and Bill 40. Similar to genetic traits, the medical conditions used to discriminate against the individuals were not based on demonstrated physical limitations but were instead based on perceived risks of injury or disease. The SCC's decision may accordingly provide precedential value for future genetic discrimination cases due to the analogous reasoning applied to perceived medical risks.

Adapting the SCC's argument on perceived disability, it is likely that genetic discrimination claims can be interpreted under "disability" if "genetic characteristics" does not become an enumerated ground of discrimination under Ontario's *Human Rights Code*. Ontario's *Human Rights Code* prohibits discrimination in employment on the basis of disability.⁶⁵ It is the Ontario Human Rights Commission's policy that

⁵⁹ *Ibid* at para 14.

⁶⁰ *Ibid* at para 85.

⁶¹ *Ibid* at para 81.

⁶² *Ibid* at para 84.

⁶³ *Ibid* at para 85.

⁶⁴ *Ibid* at para 76.

⁶⁵ RSO 1990, c H-19 at s. 5(1).

“disability” includes “past, present and perceived disabilities”.⁶⁶ Genetic characteristics can be understood as a type of perceived disability and would likely protect individuals from discriminatory conduct.

Genetic Discrimination and Insurance

What is an Actuarial Basis?

Insurers are currently permitted to discriminate in specific instances where there is an “actuarial basis” for the discrimination. An actuarial basis is an accounting method to calculate the amount of contributions into an insurance or pension fund. Due to the nature of the insurance industry, statistical probability of risk associated with factors such as age, sex or marital status are materially relevant factors that affect a risk analysis. Insurers can consequently differentiate based on grounds that would be considered discriminatory and illegal in other contexts.

Bill 40, if passed, would amend the *Human Rights Code* to create an exception for insurance-based distinctions that may have otherwise been discriminatory:

Restrictions for insurance contracts, etc.

22.1 The right under sections 1 and 3 to equal treatment with respect to services and to contract on equal terms without discrimination because of genetic characteristics is not infringed if a contract of automobile, life, accident or sickness or disability insurance or a contract of group insurance between an insurer and an association or person other than an employer, or a life annuity, differentiates or makes a distinction, exclusion or preference on reasonable and *bona fide* grounds because of genetic characteristics.

Such an exception is not without precedent; Ontario’s *Human Rights Code* outlines that discrimination based on age, sex, marital status, or family status is permitted in benefits plans if the plan is compliant with the *Employment Standards Act, 2000*.⁶⁷ In turn, O. Reg 286/01 of the *ESA* permits an employee benefit, pension, superannuation plan, group insurance plan, or fund to consider age, sex or marital status in calculating benefits where those considerations are made on an actuarial basis. Section 1 of the regulation defines an “actuarial basis” as:

...the assumptions and methods generally accepted and used by fellows of the Canadian Institute of Actuaries to establish, in relation to the contingencies of human life such as death, accident, sickness and disease, the costs of pension benefits, life insurance, disability insurance, health insurance and other similar benefits, including their actuarial equivalents

⁶⁶ Ontario Human Rights Commission, “Disability”, online: *Ontario Human Rights Commission* <http://www.ohrc.on.ca/en/code_grounds/disability>.

⁶⁷ *Supra* note 64 at ss. 25(2) and 25(2.1)

The SCC has upheld the insurance practice of considering distinguishing factors where there is an actuarial basis. In *Zurich Insurance Co v Ontario (Human Rights Commission)*, the SCC found that an insurer did not discriminate against an insured individual by charging him higher automobile insurance premiums because of his age, sex and marital status.⁶⁸ While charging higher premiums to a young, unmarried male driver was *prima facie* discrimination contrary to Ontario's *Human Rights Code*, s. 22 (then s. 21) justified the discrimination as reasonable. Section 22 allows insurers to differentiate on reasonable and *bona fide* grounds in auto insurance policies because of age, sex, marital status, family status, or disability.

The SCC accepted that the premiums were based on statistical evidence which demonstrated that young drivers are proportionately involved in more serious accidents than other comparable groups of drivers.⁶⁹ The SCC further found that there was no practical alternative to the usage of these statistics to classify risks.⁷⁰ The statistical evidence coupled with the lack of practical alternatives meant that the insurer possessed a valid actuarial basis to charge higher premiums to the insured individual.

Due to the constitutional challenge against the *GND*A and the insurance exemption in Bill 40, it is natural to expect lingering anxiety over whether insurers can utilize genetic data to disadvantage consumers. While insurers may argue that genetic predispositions are relevant and material facts when calculating policies and premiums, it remains to be seen whether genetic traits will be a justifiable consideration under an actuarial analysis.

Will Genetic Characteristics Affect Insurance Policies?

As a result of the *GND*A, individuals cannot be obliged to undergo genetic testing or to disclose their test results as a condition of insurance coverage. The Act prohibits insurance companies and their agents from collecting, using or disclosing the results of genetic tests without an individual's written consent. For the moment, genetic traits cannot disentitle people from insurance coverage and premiums cannot be based on a genetic risk of developing serious medical conditions.⁷¹

Insurers have expressed strong concern regarding how non-disclosure of genetic traits will affect the industry. It has been argued that "adverse selection" may occur whereby insurers are confronted with loss arising from an increased probability of risk not factored in at the time of the transaction. In other words, if genetic test disclosure was forbidden then an insurance company would be saddled with heightened risk of losses

⁶⁸ [1992] 2 SCR 321 at para 43.

⁶⁹ *Ibid* at para 35.

⁷⁰ *Ibid* at para 37.

⁷¹ *Supra* note 18.

from otherwise uninsurable individuals without a corresponding increase in premiums to offset the risk.⁷²

The evidence that adverse selection would occur as a result of undisclosed genetic information still requires further analysis and scrutiny. However, some studies have allayed apprehension that adverse selection would be a prevalent issue. An actuarial study into the link between genomic data and insurance indicated that the presence of high-risk mutations is rare enough in the general population that insurers in reasonably large and well-established markets likely will not suffer a drastically increased cost.⁷³ Furthermore, many genetic risks are small enough and are so closely tied with common health indicators such as blood pressure, cholesterol and diet that they may not meaningfully influence premiums.⁷⁴ Despite that, it is important to recall how inquiries into the full impact of genetic traits on insurance policies are still speculative in nature without more expansive research to draw conclusions from.

Guidance for Workplaces

While it is not yet a pervasive issue, legal disputes surrounding genetic discrimination in employment are likely to become more frequent as genetic testing grows in popularity and accessibility. Genetic discrimination fears are largely fueled by apprehension that employers will be able to exclude or remove people from employment purely based on their perceived health limitations. Employers could take advantage of this information to mitigate the prospect of employing individuals who may develop future disabilities or illnesses that they would have to accommodate. On the other hand, employees can become reluctant to undergo genetic testing that could provide them valuable health diagnostics since those diagnostics could be used to deny them opportunities.

Employers keen to know the genetic characteristics of their employees should be cautious about trying to escape their accommodation duties. As demonstrated by *Boisbriand*, perceived disability is a ground of discrimination and distinguishing amongst employees using speculative criteria such as genetic traits can expose employers to human rights claims. Employers should also be wary of engaging in efforts to reduce their likelihood of encountering workplace disability or accommodation situations. Such behaviour can be considered callous and possibly bad faith conduct.

Employers may also find difficulty when attempting to justify a genetic distinction based on the needs of their work environment. There is currently no reliable evidence to indicate that certain work environments have a causal link to hastening the onset of

⁷² Angus Macdonald, "The Actuarial Relevance of Genetic Information in the Life and Health Insurance Context" (July 2011), online: *Office of the Privacy Commissioner of Canada* <https://www.priv.gc.ca/en/opc-actions-and-decisions/research/explore-privacy-research/2011/gi_macdonald_201107/>.

⁷³ *Ibid.*

⁷⁴ *Ibid.*

genetic disease.⁷⁵ There is also an absence of empirical data to suggest that genetic mutations correlate to an amplified vulnerability to occupational illness or injury.⁷⁶

Prudent and progressive employers should treat accommodations arising from genetic traits as they would any other workplace disability. If an employee's medical condition manifests as a result of their genetic characteristics, and the employee volunteers that information, then the employer should engage in good faith efforts to accommodate the employee and promote their full inclusion in the workspace. If the employer receives any genetic data that would support the accommodation, it should be held in strict confidence as private medical material.

Conclusion

As genetic material becomes easier to obtain and interpret, the law will accordingly have to respond in order to adapt to changing societal expectations. The federal government has been proactive in implementing human rights and labour protections to safeguard against mounting genetic screening concerns. Along with the SCC's acknowledgement of how genetic technology advancements will affect the law's understanding of workplace disability, anti-genetic discrimination measures are likely to further precipitate into provincial legislation. Ontario's Bill 40 is specifically that type of measure. If successfully passed, the bill would ensure freedom from discrimination in employment based on genetic characteristics.

While it is not clear how the interaction will play out between GNDA's broad prohibitions on the collection and use of genetic testing with the limited exemption for insurers in Bill 40, these legislative endeavours nonetheless indicate a pre-emptive effort to counteract genetic discrimination before it can proliferate into a more widespread legal issue. These changes in employment law should be monitored since the innovations, usage and fears of genetic testing all show no signs of subsiding.

About the Author

Ryan Edmonds is the principal lawyer of Ryan Edmonds Workplace Counsel, a boutique firm that provides workplace law services to both employers and employees. Prior to starting his own practice, Ryan was a lawyer in the top-ranked labour and employment law group of national law firm and clerked at the Ontario Labour Relations Board, where he was seconded during his articles. An adjunct professor at Osgoode Hall Law School where he teaches employment law, Ryan has authored a number of award-winning law journal articles and frequently contributes to various industry publications. Ryan is active in the community. In addition to being a founding director of Start Proud/Out on Bay Street, he is currently an executive of the Canadian Association of Non-Organized Employees and a former member of the OBA's Equality Committee.

⁷⁵ American Civil Liberties Union, "Fact Sheet: Genetic Discrimination in the Workplace", online: *American Civil Liberties Union* <<https://www.aclu.org/other/fact-sheet-genetic-discrimination-workplace>>.

⁷⁶ *Ibid.*