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DNAnonymous: SCC upholds Genetic Non-Discrimination Act, affirming individualsâ€™ right to privacy over genetic information

An individual's genetic composition is arguably one of the most personal and private types of information out there. As science and technology continue to develop, the collection, use, and disclosure of genetic information has increased exponentially. Medical genetic testing has become a key tool in helping to diagnose and treat complicated illnesses and commercial genetic testing kits, such as 23andMe, have expanded in popularity. All of this has resulted in an exponential increase in the amount personal data being collected in our everyday lives.

Yet, imagine a world where you were fired from your job because – although you were not yet sick – your employer learned you had a gene which would eventually develop an illness in the future. Or, a world where you could not obtain health insurance without undergoing mandatory genetic testing, and were then denied insurance or had your premiums increased based on the results.

These are examples of real-life events recounted by Liberal Senator Jim Cowan in support of his proposed legislation, the *Genetic Non-Discrimination Act* ("*Genetic NDA*").

The *Genetic NDA* criminalizes compulsory genetic testing and non-voluntary collection, use or disclosure of genetic test results in the context of contracts and the provision of goods and services. The legislation has specific carve-outs for health care practitioners and researchers, but aims to protect individuals from forced genetic testing and non-voluntary disclosure of genetic test results that may lead to genetic discrimination.

The legislation also amended the *Canadian Human Rights Act*, to prevent discrimination based on genetic characteristics, and the *Canada Labour Code*, to prevent forced genetic testing and involuntary use or disclosure of results of genetic tests.

On July 10, 2020, the Supreme Court of Canada upheld the *Genetic NDA* as constitutional, in a decision that acknowledges the importance of autonomy and privacy over an individual's genetic information.

Legislative Background

On May 4, 2017, the *Genetic NDA* received royal assent, following a somewhat unusual course through Parliament. Originally a private member's bill introduced by Senator Jim Cowan, the bill was not supported by Cabinet, yet passed Senate unanimously and was approved in the House with 222 voting in favour and 60 against.

After the legislation received Royal Assent, the Government of Quebec referred the constitutionality of the legislation to the Quebec Court of Appeal. The Government of Quebec argued that the legislation was unconstitutional because it seeks to regulate the use of genetic information by insurance companies and employers, which falls under provincial jurisdiction.

Interestingly, since the legislation did not have the support of the Liberal Cabinet at the time it was passed, the Attorney General for Canada also argued on appeal that the law was unconstitutional. An *amicus curiae* (friend of the court) was therefore appointed to argue in favour of the legislation.

The Quebec Court of Appeal found that the legislation fell outside Parliament's authority to make criminal law and was therefore unconstitutional. The Canadian Coalition for Genetic Fairness appealed the decision to the Supreme Court of Canada.

Supreme Court of Canada Upholds *Genetic NDA*

In an important decision for genetic privacy rights, a 5-4 majority of the Supreme Court held that the *Genetic NDA* was constitutional, finding that it was a valid exercise of Parliament's criminal law power.

In order to answer the constitutional question, the Court looked at whether the *Genetic NDA* was enacted for a valid criminal law purpose. While the majority agreed in the result, they differed in their reasoning.

In the reasons delivered by Justice Karakatsanis, three of the Supreme Court Justices found that:

- the pith and substance of the law is to combat genetic discrimination and the fear of genetic discrimination; and
- the legislation was supported by valid criminal law purposes, including protecting autonomy, privacy and

equality in public health.

The Court noted that forced genetic testing (prohibited by section 3) poses a clear threat to autonomy and an individual's privacy interest in not finding out what their genetic makeup reveals and that forced collection, use or disclosure (prohibited by sections 4 and 5) threatens autonomy and privacy because it compromises an individual's control over access to their genetic information.

In the reasons delivered by Justice Côté, two of the Supreme Court Justices reasoned that:

- the pith and substance of the law is to protect health by prohibiting conduct that undermines the individual's control over intimate information revealed by genetic testing; and
- the legislation was supported by a valid criminal law purpose because it suppresses a threat to health (namely, it targets the detrimental health effects occasioned by people foregoing genetic testing out of fear of how the results could be used).

While the majority reasons differ, they collectively acknowledge that an individual's right to autonomy and privacy over genetic information is paramount. The Court accepted that many individuals that chose to undergo genetic testing may not want to share those results and that other individuals may not even wish to undergo testing in the first place, particularly if they do not wish to know whether they will encounter health issues in the future.

Similarly, the reasons also recognize that the negative effects occasioned by the fear of genetic discrimination, including individuals choosing to forego important genetic tests out of fear the results will be used against them, is an important public health measure that warrants protection.

The decision is an important reminder of the paramountcy of autonomy and privacy over genetic information, and the Supreme Court of Canada's reasoning and commentary on these issues will likely guide issues in genetic privacy going forward.

What the Genetic NDA means for you

The Supreme Court of Canada's ruling on constitutionality means the *Genetic NDA* is here to stay. The decision has wide ranging implications for industries across Canada.

The prohibitions under the *Genetic NDA* cast a wide net, precluding forced testing and collection, use or disclosure of genetic information in contractual relationships and in the provision of goods and services. Penalties under the *Genetic NDA* can be up to $1,000,000 in fines and 5 years imprisonment.

The provisions of the *Genetic NDA* will impact many industries including the adoption industry, consumer genetic testing, government services, and housing. If you operate in an industry where you collect genetic information (and are not covered by an exemption) it will be important to understand the prohibitions in the legislation, and to ensure genetic information is not unlawfully collected, used or disclosed both within your organization and that it is not shared with other companies contrary to the legislation.

Two of the biggest areas affected are employers and insurance companies.

Employers must become familiar with the obligations under the legislation and ensure they do not request sensitive genetic information for the purposes of employment. As an example: in the United States (before their anti-genetic discrimination legislation), some employers had explored genetic pre-dispositions as defences to certain WSIB claims. The provisions of the *Genetic NDA* would likely prohibit such conduct.

The decision will also impact the insurance industry (which intervened on the appeal). The insurance industry argued that it should be entitled to the information from genetic testing results to help its risk assessment and underwriting processes. While the Supreme Court of Canada acknowledged that the legislation may adversely impact the industry, its decision reflects that, on balance, the rights of the individual’s privacy prevail.