

Preventing Genetic Discrimination

Canada remains the only G7 country without specific protections in place to prevent genetic discrimination. As a result, Canadians who undergo genetic testing can be compelled by insurance companies and employers to disclose their results and may be denied employment or insurance based on their genes. It is time for the law to catch up with science and bring an end to genetic discrimination in Canada.

Failure to safeguard genetic test information will have lasting consequences for the health and wellbeing of all Canadians. Citing genetic discrimination, some families do not participate in studies that could have life-changing diagnostic implications for their seriously ill children.

Canadians should never have to choose between potentially life-saving medical tests and employment or insurance.

Governments continue to invest billions of dollars in promising genome research, the benefits of which will be diminished and degraded due to genetic discrimination. Given the increasingly important role of genetic testing in identifying, treating, and preventing disease, genetic discrimination is a serious issue about which all Canadians should be concerned.

Jewish Canadians are particularly susceptible to genetic discrimination, with the discovery of certain genetic markers disproportionately prevalent among Jews that indicate an elevated risk for breast and ovarian

cancer. When tested and treated, those with this marker significantly reduce the chances of developing these cancers. However, fear of discrimination motivates some to forego crucial genetic tests, a decision that could have a serious impact on their health and the health of their families.

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There is clear, nonpartisan consensus at the federal level that the status quo must be changed and that Canadians should be protected from genetic discrimination. In previous parliaments, Liberals, Conservatives and New Democrats have introduced legislation, including a government bill, C-68, introduced on June 9, 2015. At a CIJA-sponsored debate during the last federal election, representatives of all three parties committed to passing legislation to prohibit genetic discrimination if they were to form government.

Concerted action is required at both federal and provincial levels to ensure that Canadians cannot be discriminated against based on their genes, regardless of where they work or reside.

Federally, we encourage all Members of Parliament to support Bill S-201, the Genetic Non-Discrimination Act, which was passed by the Senate in April 2016.

As insurance and employment are provincial responsibilities, we encourage provincial governments to enact complementary legislation to reinforce the federal initiative.

Given these two important areas of provincial jurisdiction, the Senate sought input from the provinces before passing S-201. Ten of 13 provinces and territories responded. None raised any concern pertaining to the constitutionality of the bill or suggested that genetic discrimination was beyond the purview of the federal government.

This consensus was reinforced by the Senate testimony of Professor Bruce Ryder of Osgoode Hall Law School and Pierre Thibault, Assistant Dean at the University of Ottawa Law School, both of whom consider S-201 to be constitutionally valid.

As Professor Ryder noted, S-201 does not contain a licensing scheme or industry regulations. It places a prohibition on requiring individuals to undergo genetic testing or to disclose the results of a test, and on the use of genetic test results without written consent. These prohibitions apply to “any person,” not a particular industry or type of actor.

The purpose of S-201 is to address a significant social problem across Canada. By prohibiting and penalizing genetic discrimination, Parliament would be encouraging Canadians to undergo genetic testing that offers tremendous, potentially life-saving, health benefits. This is the objective of S-201, which falls squarely within the federal domain, and we encourage all Members of Parliament to support it.

KEY POINTS

- Despite investing billions of dollars in promising genome research, Canada remains the only G7 nation without specific protections in place to prevent genetic discrimination.
- Failure to safeguard genetic test information will have lasting consequences for the health and wellbeing of all Canadians.
- Concerted action is required at both federal and provincial levels to ensure that Canadians cannot be discriminated against based on their genes, regardless of where they work or reside.
- It is time for the law to catch up with science and bring an end to genetic discrimination in Canada.
- We encourage all Members of Parliament to support Bill S-201, the Genetic Non-Discrimination Act, which was passed by the Senate in April 2016.
- We encourage provincial legislatures to pass complementary legislation, with a specific focus on employment and insurance.