



May 18, 2016

### **ASHG Policy Statement on the Canadian Genetic Non-Discrimination Act (S-201)**

The American Society of Human Genetics supports the passage of Bill [S-201, the Genetic Non-Discrimination Act](#), by the Parliament of Canada, to ensure that all Canadians can benefit from genetics-based clinical advances without fear of genetic discrimination.

At a time when genetic testing is increasingly being incorporated into clinical care and researchers are performing analyses of human genomes on an unprecedented scale, it is critical that the genetic information of patients and research participants alike is not misused. There need to be laws in place to ensure not only that an individual's genetic information remains private, but also that their genetic information cannot be used in a way that harms them. Such protections are necessary to reassure members of the public that they can participate in genetic research or undergo a genetic test without fear that their genetic information will be used to discriminate against them.

ASHG has long supported the establishment of strong protections against genetic discrimination. For thirteen years, the Society [advocated for the Genetic Information Nondiscrimination Act](#) in the United States. It was enacted in 2008, establishing new protections for Americans against genetic discrimination in the workplace or through health insurance. The Society continues to advocate for the robust implementation of the law.

As an international Society that represents genetics professionals in many countries, ASHG recognizes the need for protections against genetic discrimination worldwide. Bill S-201 protects individuals from being required to undergo a genetic test, or disclose the results of a test, as a condition of acquiring a good or service or entering into a contractual agreement. In addition, it prohibits employers from requiring employees to undergo genetic testing or disclose testing results, or taking discriminatory action against employees who refuse to undergo genetic testing or reveal testing results. It also amends the Canadian Human Rights Act to prohibit discrimination on the ground of genetic characteristics.

Without adequate protection, the fear of genetic discrimination in Canada is not purely theoretical. For example, a Canadian study led by ASHG member Yvonne Bombard, PhD, demonstrated that 86% of surveyed people at risk for Huntington's disease feared discrimination against themselves and their children<sup>i</sup>, and that 40% reported experiences of discrimination by insurers, employers, and in other contexts<sup>ii</sup>. It is critical that Bill S-201 is passed into law so that Canadians can participate in genetics research and make use of medical advances that stem from such research without fear of discrimination.

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<sup>i</sup> Bombard Y., Palin J., Friedman J.M., *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): 217-226.

<sup>ii</sup> Bombard Y., Veenstra G., Friedman J.M., *et al.* [Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey](#). *BMJ.* (2009); 338: b2175.