



Standing Senate Committee on Human Rights
The Senate of Canada
Ottawa, Ontario
Canada, K1A 0A4

February 26, 2016

Dear Committee Members,

On behalf of the Centre for Israel and Jewish Affairs (CIJA), the advocacy agent of the Jewish Federations of Canada, I am pleased to submit this written brief in support of Bill S201: An Act to prohibit and prevent genetic discrimination. Thank you for accord us an opportunity to contribute on such an important issue for our community, and indeed for all Canadians.

CIJA is a national, non-partisan, non-profit organization dedicated to improving the quality of Jewish life in Canada by advancing the public policy interests of Canada's organized Jewish community. CIJA is a member of the Canadian Coalition for Genetic Fairness, but unlike the other 15 member organizations, we do not advocate for those impacted by any particular disease or disorder.

We represent a diverse community of hundreds of thousands of Canadians who are acutely at risk of being discriminated against based on their genes. In our testimony before this committee regarding the previous iteration of Senator Cowan's bill, CIJA presented the specific concerns of the Jewish community regarding genetic discrimination, particularly surrounding the BRCA genetic markers for breast and ovarian cancer that are disproportionately prevalent among Jews of European descent.

Since testifying, we have encountered numerous examples of Jewish Canadians facing genetic discrimination. One example that is particularly illustrative involved a young woman beginning her career as a lawyer. Her physician advised her that screening for the BRCA markers would be advantageous for her long-term health. After all, the Canadian Cancer Society has noted that screening and prophylactic intervention can reduce the risk for women with the BRCA marker of developing breast cancer by close to 90 percent. However, this young lawyer's physician also cautioned her that getting tested could limit her career prospects. Disclosure of genetic test results, which an employer or insurance company could compel, could prevent her from becoming a partner in a law firm or accessing insurance to establish her own practice. No one should be forced to choose between their health and their livelihood in such a way.

Genetic discrimination is not confined to particular diseases or communities. Hypertrophic cardiomyopathy, a heart condition manifest in one in every 500 people, is an example of how genetic discrimination has the potential to impact all Canadians. This inherited disorder is the leading cause of sudden death among young athletes. Early identification provides the best opportunity for preventative measures to reduce mortality, both clinically and through lifestyle changes. With a growing number of genes associated with hypertrophic cardiomyopathy, Canadians should be encouraged to take advantage of the potentially life-saving health benefits of genetic testing. Sadly, genetic discrimination all too often forms a barrier to important diagnostic and treatment options, which Dr. Ronald Cohn eloquently described as "paralyzing" in his testimony before the committee.



With genetic medicine advancing at an exponential rate and the costs of genetic testing and genome sequencing falling rapidly, genetic discrimination is a problem that is only going to get worse without legislative action. In our previous testimony, CIJA noted the broad-based consensus that existed at the time, transcending party lines, on the imperative to prevent genetic discrimination in Canada. I am pleased to report that this consensus has developed even further since.

In June 2015, the Conservative government followed up on their throne speech commitment to prevent genetic discrimination by introducing Bill C-68: the Protection Against Genetic Discrimination Act. Unfortunately, the timing of the bill's introduction so close to an election meant that it was unable to progress beyond first reading.

During the federal election campaign that followed, CIJA, in partnership with UJA Federation of Greater Toronto, hosted representatives of all three major federal parties – the Liberals, Conservatives and NDP – for a debate on issues of concern to the Jewish community. Genetic discrimination featured prominently. As the Globe and Mail reported, all three representatives, who included the previous and current Finance Ministers, were unified in their commitment to prohibit discrimination on the basis of genetic test results if elected to government.

Consensus on preventing genetic discrimination also transcends jurisdictions, with many provinces interested in advancing complementary legislation. As Professor Bruce Ryder noted in his testimony before the committee, the prohibition of genetic discrimination can be considered an area of shared jurisdiction between federal and provincial legislatures. Over the last several months, CIJA has held preliminary discussions with representatives in government and opposition from nine of ten provinces to discuss the possibility of passing complementary legislation. As Professor Ryder mentioned, it is often the role of the federal parliament to provide national leadership by establishing basic standards, with provincial legislation later supplementing federal law. In nearly every case, the provincial representatives we spoke with expressed some interest in pursuing the issue, and with federal leadership in the form of Bill S-201 we are hopeful that they will.

Bill S-201 represents the pinnacle of what federal legislation can accomplish on this deeply troubling issue. We recommend that the committee refer this important bill to the Senate for third reading without amendment.

We would welcome an opportunity to engage further on this issue, and thank you for your consideration of our views.

Sincerely,

A handwritten signature in black ink, appearing to read "Noah Shack", written over a light blue horizontal line.

Noah Shack
Director, Policy
The Centre for Israel and Jewish Affairs