

WSSR WORKSHOPS ON SOCIAL SCIENCE RESEARCH

The Path to Preventing Genetic Discrimination: Understanding and learning from the legislative process of Bill S-201

Honourable James Cowan

Former Nova Scotia Senator and Senate Liberal Leader

April 6, 2018

9:00am – 4:30pm

Summary

With advancements in health research and human genomics, access to genetic information has opened up a completely new world of risks for everyday Canadians. Genetic testing has become widely accessible in recent years and, until recently, there were no measures in place to protect Canadians from the possible repercussions. On April 6th, join former Nova Scotia Senator, Honourable James Cowan, to discuss the path that he took to put a stop to genetic discrimination here in Canada.

This workshop will provide participants with an overview of the process that Cowan undertook, from the individual consultations with constituents to the Bill's final assent, using this important example as a jumping-off point to discuss the various processes available in Canada through which to elevate key social issues to the top of the political agenda.

Outline

Morning

Bill S-201 - The Legislative Process: from issue to assent

- a. The issue – What is genetic discrimination? Why this issue?
- b. The landscape – What avenues existed to address the issue?
- c. The process – What strategy was settled on?
- d. The key players – Who was involved and what coalitions were built?
- e. The challenges – What were the roadblocks and how were they confronted?

Understanding and Learning from this Experience

- a. What processes are available to Canadians to advance an issue that they care about?
- b. How do you choose between one strategy or another? What alliances need to be made? What information is required? Are some strategies more effective than others?

Afternoon

Developing a Strategy: Getting your issue on the agenda

As a group, participants will select an important issue and explore the best strategies available to push that issue forward, devising the most efficient and effective plan to escalate this issue and affect change.

Examples of issues that the group may choose to work through during this session include (among others): the recent rise in allegations of sexual harassment and misconduct, the justice system's failures in the treatment of Aboriginal people in Canada, the renaming or removal of monuments and landmarks following revelations of the historical misdeeds or contentious views of the individuals they represent.



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Required Readings*

- Cheadle, Bruce (2016) "Canadian senator wins award for work on genetic discrimination". *Globe and Mail*, June 27, <https://www.theglobeandmail.com/news/national/canadian-senator-wins-award-for-work-on-genetic-discrimination/article30623475/>
- Desantis, Gloria C. and Nick J. Mulé (2017) "Advocacy: A Contested yet Enduring Concept in the Canadian Landscape" in *Shifting Terrain: Nonprofit Policy Advocacy in Canada*, Nick J. Mulé, and Gloria C. Desantis (eds.) Montreal: McGill-Queen's University Press, pp. 3-32. <http://0-www.deslibris.ca.mercury.concordia.ca/ID/452387>
- Nicholls, Stuart G. and Patrick Fafard (2016) "Genetic discrimination legislation in Canada: moving from rhetoric to real debate" *CMAJ: Canadian Medical Association Journal*, 188(11): 788-789. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4978570/>
- Parliament of Canada. "Legislative Process". *Compendium of Procedure*, https://www.ourcommons.ca/About/Compendium/LegislativeProcess/c_g_legislativeprocess-e.htm
- Tasker, John Paul (2017) "MPs reject Liberal government's attempt to gut genetic discrimination bill". *CBC News*, March 7, <http://www.cbc.ca/news/politics/cowan-genetic-discrimination-bill-lobbyists-1.4013886>
- Thomas, Paul (2003) "Comparing the Lawmaking Roles of the Senate and the House of Commons" in *Protecting Canadian Democracy: The Senate you never knew*, Serge Joyal (ed.) Montreal: McGill-Queen's University Press, pp. 189-228. <http://reserves.concordia.ca/ares/ares.dll/plink?14EF20F3>

Recommended Readings*

- Adjin-Tettey, Elizabeth (2013) "Potential for Genetic Discrimination in Access to Insurance: Is there a dark side to increased availability of genetic information?" *Alberta Law Review*, 50(3): 577-614.
- Bill S201: An Act to prohibit and prevent genetic discrimination* (2017) 1st Reading Dec. 8, 2015, 42nd Parliament, 1st session, <http://www.parl.ca/DocumentViewer/en/42-1/bill/S-201/royal-assent>
- Joly, Yann, Ida Ngueng Feze, Lingqiao Song, Bartha M. Knoppers (2017) "Comparative Approaches to Genetic Discrimination: Chasing Shadows?" *Trends in Genetics*, 33(5): 299-302.
- Kondro, Wayne (2017) "Canada's new genetic privacy law is causing huge headaches for Justin Trudeau". *Science Magazine*, March 10, <http://www.sciencemag.org/news/2017/03/canada-s-new-genetic-privacy-law-causing-huge-headaches-justin-trudeau>
- Singh, Kshitij Kumar (2014) *Biotechnology and Intellectual Property Rights: Legal and social implications*. New Delhi: Springer.

*If you are registered for non-credit and are unable to locate the readings, please contact us at wssr@concordia.ca

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