

CGP

Centre of Genomics and Policy  
Centre de génomique et politiques



McGill

Submission to the Standing Senate Committee on  
Legal and Constitutional Affairs regarding Bill S-201,  
*An Act to prohibit and prevent genetic discrimination*

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## About the Center of Genomics and Policy

The Centre of Genomics and Policy (CGP) of McGill University welcomes the opportunity to present this brief to the Standing Committee on Legal and Constitutional Affairs regarding Bill S-201, *An Act to prohibit and prevent genetic discrimination*.

Established in 2009, the CGP is at the crossroads of the legal, medical and public policy fields. The CGP consist of research assistants, academic associates and researchers with multidisciplinary expertise in law, ethics, sociology and medical sciences. The CGP promotes prospective structuring and guidance for both research in genomic health sciences and its applications. Within a multidisciplinary perspective and in collaboration with national and international partners, the CGP analyzes the socio-ethical and legal norms influencing multiple aspects of the promotion, prevention and protection of human health.

The CGP is internationally recognized for its expertise in research and policy on genetic discrimination. From the first Canadian review on genetic discrimination for the Law Reform Commission of Canada<sup>1</sup> by its founding member, Bartha M. Knoppers in 1991 to the 2004 creation and scientific leadership of the Canadian Task Force on Genetics and Life Insurance<sup>2</sup> and, more recently, the 2013 first systematic review of the existing studies on genetic discrimination by Research Director Yann Joly and colleagues<sup>3</sup>, the CGP has pioneered research on this subject.

We appreciate the opportunity to comment on Bill S-201 and to draw the attention of the Committee to certain elements relevant from legal, ethical and public health perspectives. We would welcome the opportunity to appear before the Committee to present on the content of our submission, which was prepared by Ida Ngueng Feze Esq, Me Shahad Salman, Pr. Yann Joly, PhD, Ad.E, Research Director of the CGP and Pr. Bartha M. Knoppers, PhD, OC, OQ, Ad.E, Canada Research in Law and Medicine, Director of the CGP.

### **This Submission has been endorsed by the following individuals and organizations:**

- Pavel Hamet, OQ, MD, PhD, FRCP, FAHA, FCAHS, Professor of Medicine, Université de Montreal, Canada Research Chair in Predictive Genomics, Chief of Service of Genetic Medicine, CHUM
- Jacques Simard, PhD, FACSS, Professor of Molecular Medicine, Université Laval, Canada Research Chair in Oncogenetics, Director of the Cancer Genomics Laboratory at CHUQ Research Centre/CHUL
- Martin Leblanc, President, CEO and co-founder of Caprion (<http://www.caprion.com/en/caprion/index.php>)

## Submissions

1. Advances in medical research have generated a greater understanding of disease and facilitated the creation of new means of prevention as well as, screening and treatment.<sup>4</sup> Through this process, an unprecedented amount of genetic information is being generated from genetic test results conducted in both clinical and research settings. This increasing availability of genetic information has raised some concerns about its use outside of the therapeutic context.<sup>5</sup> In Canada, despite the lack of evidence supporting the existence of systemic discriminatory practices based on genetic information outside of the context of Huntington's diseases<sup>6</sup>, patient groups, professional associations and the media have expressed concerns about possible discrimination risks.<sup>7</sup>

2. The Centre for Genomics and Policy of McGill University welcomes the opportunity to bring to the attention of the Committee to the following points:

### **A. Strong support for the adoption of a prohibition on genetic testing of individuals as a condition for accessing goods and services such as insurance (Clauses 3, 4 and 8)**

3. The Centre strongly supports the position of Bill S-201 to prohibit genetic testing from being required as a condition to accessing goods or services. Imposing genetic testing on individuals goes against fundamental principles of the Canadian society such as the respect for human dignity and individual autonomy. We should also point out that the current policy of the *Canadian Life and Health Insurance Association Position Statement on Genetic Testing* recommends that its members do not impose genetic testing on insurance applicants.<sup>8</sup> Thus, the proposed legislation would effectively strengthen an already existing policy beyond industry self-policing thereby providing a greater degree of accountability and appeasing popular anxiety on the matter.

### **B. Prohibition on the disclosure of genetic test results should be confined to research genetic test results (Clauses 4 and 6)**

4. Genetic test results obtained in the context of research should not be used outside of this context and more generally that of health promotion. Genetic test results obtained in the context of health research often do not meet the threshold of analytical validity, clinical validity and clinical utility and their use may also generate unforeseen legal and ethical issues<sup>9</sup>. In addition, genetic research results are very difficult to interpret and may often be contradicted by later studies.<sup>10</sup> Recent studies have demonstrated that individuals are declining or would decline participation in genetic research due to fear of genetic discrimination by third parties such as insurers and employers<sup>11</sup>. This impediment is significant at a time where genomic research and personalized medicine are expected to make substantial contributions to the improvement of health services, treatment and preventive measures. (In reference to clause 4)

5. Genetic information has the potential to significantly improve actuarial data by making them more precise. Researchers and international experts have even suggested that, in the insurance context, actuarial risk stratification should integrate genetic data in order to refine risk assessment and thereby make the setting of premiums more accurate.<sup>12</sup> Indeed, without access to genetic information derived from clinical testing, genomic risk stratification in insurance underwriting might eventually constitute unfair treatment due to actuarial/clinical inaccuracy.<sup>13</sup> To date, there has been no convincing evidence from researchers or

patient groups to demonstrate the existence of genetic discrimination in either complex, multi-factorial diseases involving genetic susceptibilities or in that of personalized healthcare.<sup>14</sup> Given the lack of evidence of GD outside of Huntington's disease and the challenge of coming up with a definition of genetic testing that is both scientifically sound and convenient to implement, the Standing Committee should consider the opportunity of preserving the statu quo (not legislating) on the disclosure of genetic test results obtained in the context of clinical care.

### C. Constitutional limitations of the Bill

6. It should be remembered that areas where cases of genetic discrimination are the most likely to manifest themselves are situated within provincial fields of competence (ex. private insurance, employment outside governmental sector, adoption) and therefore would be beyond the reach of the Bill. Nevertheless, S-201 could generate a synergistic effect that will facilitate the adoption of similar complementary legislation by provincial policymakers to better protect citizens from genetic discrimination.

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<sup>1</sup> Bartha Maria Knoppers, *Human dignity and genetic heritage* (Ottawa: Law Reform Commission of Canada, 1991).

<sup>2</sup> Bartha M. Knoppers and Yann Joly, "Physicians, genetics and life insurance" *Canadian Medical Association Journal* (2004) 170(9), pp. 1421-1423.

<sup>3</sup> Yann Joly, Ida Ngueng Feze and Jacques Simard, "Genetic discrimination and life insurance: a systematic review of the evidence" (2013) *BMC Medicine* 11:25.

<sup>4</sup> Yann Joly, Maria Braker and Michael Le Huynh, "Genetic discrimination in private insurance: global perspectives" (2010) *New Genetics and Society* 29(4), pp. 351-368.

<sup>5</sup> Yann Joly, Hilary Burton, Bartha Maria Knoppers et al, "Life insurance: genomic stratification and risk classification" (2014) *European Journal of Human Genetics* 22, pp. 575-579.

<sup>6</sup> Yvonne Bombard, Elizabeth Penziner, Joji Decolongon et al, "Managing genetic discrimination: strategies used by individuals found to have the Huntington disease mutation" (2007) *Clinical Genetics* 71, pp. 220-31; Yvonne Bombard, Elizabeth Penziner, Oksana Suchowersky et al, "Engagement with genetic discrimination: concerns and experiences in the context of Huntington disease" (2008) *European Journal of Human Genetics* 16, pp. 279-89; Yvonne Bombard, JoAnne Palin, Jan M. Friedman et al, "Beyond the patient: the broader impact of genetic discrimination among individuals at risk of Huntington disease" (2012) *American Journal of Human Genetics* 159(B), pp. 217-26.

<sup>7</sup> Joly & al. (2013), *supra* note 3.

<sup>8</sup> Canadian Life and Health Insurance Association Inc. *CLHIA position statement on genetic testing*, Toronto: CLHIA, 2010.

<sup>9</sup> Ida Ngueng Feze and Yann Joly, "Can't always get what you want? Try an indirect route you might just get what you need: a study on access to genetic data by Canadian life insurers" (2014) *Current Pharmacogenomics and Personalized Medicine* 12(1).

<sup>10</sup> Bartha M. Knoppers, Yann Joly and Simard J, "The emergence of an ethical duty to disclose genetic research results: international perspectives" (2006) *European Journal of Human Genetics* 14, pp. 1170-8.

<sup>11</sup> Beatrice Godard, Annabelle Pratt, Martine Dumont et al, "Factors associated with an individual's decision to withdraw from genetic testing for breast and ovarian cancer susceptibility: implications for counseling" (2007) *Genetic Testing* 11(1), pp. 45-54; Phoenix Strategic perspectives Inc. *Survey of Canadians on Privacy-Related Issues*, Ontario: Office of the Privacy Commissioner of Canada, January 2013.

<sup>12</sup> Joly & al. (2014), *supra* note 5.

<sup>13</sup> *Ibid.*

<sup>14</sup> Joly & al. (2013), *supra* note 3.