

**IN THE SUPREME COURT OF CANADA  
(ON APPEAL FROM THE COURT OF APPEAL OF QUÉBEC)**

B E T W E E N:

**CANADIAN COALITION FOR GENETIC FAIRNESS**

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(Intervener)

- and -

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## PART I - OVERVIEW

1. The Canadian College of Medical Geneticists (“CCMG”) is a national organization of over 300 medical genetics professionals — physicians and clinical doctoral scientists — working on the front lines of patient care to provide medical genetic testing and related services to the Canadian public. CCMG’s overarching mandate is to provide standardized, safe, and responsible medical genetic testing and services all in support of protecting and enhancing the health of Canadians.

2. In the *Genetic Non-Discrimination Act*<sup>1</sup> (“*GNDA*”), Parliament legislated prohibitions to protect the health of Canadians in vulnerable situations. These prohibitions protect Canadians from harm that flows from a public health evil: discrimination, abuse, or misuse associated with medical genetic testing and results, all of which may cause Canadians to forgo this diagnostic treatment.

3. Medical genetic testing is proving revolutionary in the diagnosis, prevention, and treatment of a wide-variety of serious and rare diseases. Due to its effectiveness, medical genetic testing is increasingly available and recommended by Canadian medical geneticists and physicians to diagnose, prevent, and treat rare diseases.<sup>2</sup>

4. There are, however, risks in offering this revolutionary diagnostic tool to the Canadian public. As medical genetic testing becomes indispensable, Canadians who undergo such testing bear significant risks in exposing to the world their most intimate and life-defining medical details - DNA, the source code of their medical health information. Canadians who seek this medical treatment become a vulnerable subset of the Canadian population.

5. In this insecure environment, Canadians are fearful of what will happen to their medical genetic testing results and information such that they avoid this vital diagnostic tool to their own detriment. CCMG is concerned — as are Canadians — by the scant legal protection from abuse or misuse of medical genetic testing and results in Canada. The *GNDA*, in the view of CCMG, contributes to filling this gap.

<sup>1</sup> S.C. 2017, c. 3.

<sup>2</sup> Testimony of Dr. Gail Graham, Past-president of CCMG, Proceedings of the Standing Committee on Human Rights, November 24, 2016, p. 6.

6. CCMG submits that Parliament’s decision to protect the health of Canadians by enacting the *GND*A constitutes a valid exercise of its power to legislate in the domain of criminal law. Parliament has wide ambit to enact legislation, under its criminal law power, aimed at protecting the health of Canadians.

7. This Court has held that Parliament may validly exercise its criminal law-making power to, *inter alia*, target public health “evils”. The *GND*A aims at curtailing the abuse or misuse of medical genetic testing – harmful conduct that endangers the health of Canadians, particularly the vulnerable population of Canadians who need to undergo such testing.

## **PART II - QUESTION IN ISSUE**

8. The question referred to the Quebec Court of Appeal was the following:

Is the *Genetic Non-Discrimination Act* enacted by sections 1-7 of the Act to prohibit and prevent genetic discrimination (S.C. 2017, c. 3) *ultra vires* to the jurisdiction of the Parliament of Canada over criminal law under paragraph 91(27) of the *Constitution Act, 1867*?

9. The CCMG’s submissions are relevant to the following issue raised by this Appeal: does the *GND*A have a valid criminal law purpose?

## **PART III - STATEMENT OF ARGUMENT**

### ***Parliament has wide ambit to enact criminal laws to protect the health of Canadians***

10. This Court’s jurisprudence establishes that, for federal legislation to constitute valid criminal law, the legislation must fulfill three requirements: (1) it is aimed at a valid criminal law purpose backed by (2) a prohibition and (3) a penalty.<sup>3</sup>

11. As the impugned provisions at ss. 1-7 of the *GND*A contain both prohibitions and penalties, the only issue for determination is whether these provisions satisfy the first requirement – a valid criminal law purpose.

<sup>3</sup> See e.g. *Reference re Firearms Act*, 200 SCC 31, para. 27; *Reference re Assisted Human Reproduction Act*, 2010 SCC 61, para. 35.

12. In the *Margarine Reference*, Justice Rand held that a valid criminal legislative purpose was generally directed at an injurious public “evil,” such as a harm against “[p]ublic peace, order, security, health, [or] morality,” but that it need not be confined exclusively to those categories.<sup>4</sup>

13. In the *GND*, Parliament identified a public health evil – the discrimination, abuse, and misuse of medical genetic testing and its results, all of which dissuade Canadians from undergoing such testing to their detriment. The *GND* therefore seeks to prohibit third-parties, except medical professionals in a medical treatment or research setting exempted in section 6, from requiring, using, or misusing medical genetic testing and results.

14. The *GND*’s exemptions further support the view that the pith and substance of the *GND* is the protection of the Canadian public’s health. Indeed, the exemption in section 6 for medical professionals helps “define the crime by clarifying its contours”.<sup>5</sup>

***“Public health evil” encompasses a broad set of behaviours and effects***

15. In enacting criminal law to protect health, Parliament’s authority is broad. In this Court’s most recent pronouncement on the scope of Parliament’s authority to use the criminal law power to legislate for the protection of health, Chief Justice McLachlin held that Parliament may target any conduct that elevates the risk of harm to the health of Canadians:

Behind the diversity of cases that have upheld criminal laws on the basis of public health evils lie three constant features. In each of these cases, the criminal law was grounded in (1) human conduct (2) that has an injurious or undesirable effect (3) on the health of the members of the public.

[...]

Parliament is entitled to target conduct that elevates the risk of harm to individuals, even if it does not always crystallize in injury. For example, Parliament may criminalize dangerous driving, despite the fact that it creates only a risk of injury, not a certainty. Where human conduct may cause injurious or undesirable effects

<sup>4</sup> *Reference re the Validity of Section 5(a) of the Dairy Industry Act*, [1949] S.C.R. 1 [*Margarine Reference*], p. 50, aff’d [1951] AC 179.

<sup>5</sup> *RJR-MacDonald Inc. v. Canada (Attorney General)*, [1995] 3 S.C.R. 199 [*RJR-MacDonald*], para. 56.



on the health of members of society, Parliament may prohibit it as a public health evil.<sup>6</sup>

16. Chief Justice McLachlin’s discussion in the *Reference re Assisted Reproduction Act* echoed earlier conclusions by Justice La Forest writing for the majority on the division of powers issue in *RJR-MacDonald*: “The scope of the federal power to create criminal legislation with respect to health matters is broad, and is circumscribed only by the requirements that the legislation must contain a prohibition accompanied by a penal sanction and must be directed at a legitimate public health evil.”<sup>7</sup>

17. The scope of Parliament’s authority to exercise the criminal law power must be flexible “given the amorphous nature of health as a constitutional matter.”<sup>8</sup> Indeed, “the criminal law must be able to respond to new and emerging matters of public concern that go to the health and security of Canadians and the fundamental values that underpin Canadian society.”<sup>9</sup>

18. Medical genetic testing is a new and emerging matter of public concern. Not only is Parliament entitled to legislate prohibitions on “injurious conduct” that may emanate from this advancement in medical science, it is reasonable to expect Parliament to do so considering the significant interests Canadians have in medical genetic testing, particularly at this early stage of our collective understanding of its benefits.

***The GNDA prohibitions aim at a legitimate public health evil***

19. The *GNDA*’s prohibitions target a legitimate public health evil. The legislative history, including testimony from various medical practitioners before various committees, supports the conclusion that there is – at the very least – a “reasonable apprehension of harm” that Parliament is seeking to protect against: the discrimination, abuse, and misuse of medical genetic testing and results, all of which dissuade Canadians from undergoing vital testing.

<sup>6</sup> *Reference Re Assisted Human Reproduction Act*, paras. 54 and 55.

<sup>7</sup> *RJR-MacDonald*, para. 32; see also *Reference Re Assisted Human Reproduction Act*, paras. 54, 55, and 62.

<sup>8</sup> *RJR-MacDonald*, para. 32.

<sup>9</sup> *Reference Re Assisted Human Reproduction Act*, para. 43.

20. The Hon. Rob Oliphant, MP, expressed the public health evil supporting the criminal prohibitions as requiring that “the knowledge we have through genetic research is protected from potential abuse and that there are as few impediments as possible to getting tested.”<sup>10</sup>

21. Parliamentary testimony from frontline researchers and clinicians bear witness and convey the fear of many Canadians who feel unsafe to undergo medical genetic testing:

When I came to Sick Kids, we started a research study on whole genome sequencing to children at the entire hospital, not just genetic patients in our division but to the entire hospital, simply to see what we can learn and how we can deal with the information ... We asked 330 patients and their families to participate in our study. I would like you to appreciate, please, that these are all families who have very sick children. They all have children with a lot of medical problems. Over 33 per cent declined to participate in a free research study because they were afraid of genetic discrimination. I have to tell you that I find that an alarming number. These families, in part, have tried to go through diagnostic odyssey for years and years, and here I am able to offer them something that likely will give them an answer; but they are declining because they are afraid of genetic discrimination.<sup>11</sup>

22. Written testimony from Dr. Yvonne Bombard explains why significant protections are called for in the circumstances. Protection from abuse of the human genetic source code is essential for providing a secure space for the availability of this vital diagnostic tool:

...[The legislation] would provide comprehensive protection for Canadians, which would prevent discriminatory experiences, allay patients’ fears, encourage their participation in genomics research, and most importantly, empower patients and their families to take preventative measures to reduce their risks for future diseases. Genetic fairness is a fundamental right, which can empower patients to live healthy, productive and meaningful lives, while also ensuring Canada remains on the cutting-edge of genomics research.<sup>12</sup>

23. Past-president of the CCMG, Dr. Gail Graham, described medical genetic testing as “a critical tool in many disciplines of medicine, not just to diagnose disease, but also to guide the selection of personalized treatments.” Further, she testified, the risk to Canadians is real and evolving:

<sup>10</sup> House of Commons Debates, September 20, 2016, 4886.

<sup>11</sup> Testimony of Dr. Ronald Cohn, Proceedings of the Standing Committee on Human Rights, October 2, 2014, 11:90.

<sup>12</sup> Dr. Yvonne Bombard, “Written Testimony to the Standing Senate Committee on Human Rights Regarding Bill S-201, An Act to Prohibit and Prevent Genetic Discrimination”, February 29, 2016, p. 8.

We can speak as doctors across our country who care for patients with genetic conditions. We can say very clearly that genetic discrimination and fear of discrimination are not just theoretical, as some have argued. We can say that it truly changes behaviour. We can say that it influences patients' decisions in clinics across the country every single day. We can say that it sits in the clinic room between us and our patients when they consider the pros and cons of a predictive genetic test for hereditary cancer, for example.<sup>13</sup>

24. In short, Canadians are fearful that if they undergo medical genetic testing their results may be misused outside of this medically-directed diagnostic context. The *GND*'s prohibitions aim at the public health evil related to the unsafe environment for medical genetic testing and the adverse consequences that arise from that unsafe environment – namely, that Canadians will avoid undergoing medical genetic testing to the detriment of their health. Patients, for example, may not receive the preventative surgical measures they need to avoid cancer if they do not undergo medical genetic testing that provides the underlying confirmation of their genetic make-up.

25. That the public health evils may not be fully known or appreciated at this time is not fatal to Parliament's exercise of its criminal law power. In *Malmo-Levine*, the majority opinion of Justices Gonthier and Binnie held that, despite gaps in our knowledge of the harms to health caused by marijuana, Parliament was still entitled to act on the basis of a "reasonable apprehension of harm."<sup>14</sup> Justice La Forest in *RJR-MacDonald* also noted that "it has long been recognized that there also exists a preventative branch of the criminal law power."<sup>15</sup>

26. The above shows that Parliament and expert opinions identified "some injurious effect" – or at least a "reasonable apprehension of harm" – if medical genetic testing is offered in an environment in which the results of that testing can be abused or misused.<sup>16</sup> Given the significant interest that an individual holds in her genetic information, it cannot reasonably be said that there is

<sup>13</sup> Testimony of Dr. Gail Graham, Standing Committee on Justice and Human Rights, November 24, 2016, p.2.

<sup>14</sup> *R. v. Malmo-Levine; R. v. Caine*, 2003 SCC 74 [**Malmo-Levine**], p. 641; see also *RJR-MacDonald*, para 41.

<sup>15</sup> *RJR-MacDonald*, para 41.

<sup>16</sup> *Margarine Reference*, p. 49-50; *RJR-McDonald*, para. 32; *Malmo-Levine*, p. 680.

“little or no threat of harm” in offering medical genetic testing in this environment of potential abuse or misuse.<sup>17</sup>

27. The debate and testimony above underlines that medical genetic testing is innovative medical science. While “the jury may still be out”<sup>18</sup> with respect to the nature of medical genetic testing and its risks, the verdict is clear on the public health evils to Canadians who cannot undergo such testing in a safe and medically-directed environment.

28. The limitations of what constitutes a valid public health evil are also flexible, as described by Chief Justice McLachlin in *Reference Re Assisted Human Reproduction Act*:

No constitutional threshold level of harm, as such, constrains Parliament’s ability to target conduct causing these evils. It is not apparent that the criminal law may only regulate the severest risks to individual’s health and safety, and not also prohibit less severe harms that are of public concern.

Parliament is entitled to use the criminal law power to safeguard the public from conduct that may have an injurious or undesirable effect on the health of members of the public, notwithstanding the provinces’ general right to regulate the medical profession.<sup>19</sup>

29. A similar principle was stated by Justice Arbour (in dissent, though not on this issue) in *Malmo-Levine*:

While there is no constitutional threshold level of harm required before Parliament may use its broad criminal law power, conduct with little or no threat of harm is unlikely to qualify as a ‘public health evil’.

Just as Parliament may determine the nature of the mental element pertaining to different crimes, it may determine the nature of the “evil or injurious effect” from which it wishes to protect the public.<sup>20</sup>

***Canadians who undergo medical genetic testing are a vulnerable population***

30. Abuse or misuse of medical genetic information is a legitimate public health concern, particularly because it involves a vulnerable population. The medical genetic test-seeking public is

<sup>17</sup> *Malmo-Levine*, p. 680.

<sup>18</sup> *Malmo-Levine*, p. 621.

<sup>19</sup> *Reference Re Assisted Human Reproduction Act*, paras. 56 and 57.

<sup>20</sup> *Malmo-Levine*, at p. 680.

a vulnerable part of the Canadian population. These Canadians undergo some of the most invasive testing in medical science and expose the details of their individual human source codes.

31. The protection of vulnerable populations provides further helpful rationale for the underlying criminal law purpose.<sup>21</sup> Chief Justice McLachlin echoes this conclusion in the *Reference Re Assisted Human Reproduction Act*: “In the context of the federalism analysis, it suffices that the protection of vulnerable groups has been recognized as a valid criminal law purpose.”<sup>22</sup>

### ***Conclusion***

32. In this case, the public health evil that is the object of these criminal prohibitions is protection from the possible adverse consequences associated with medical genetic testing if made available without adequate protection against abuse. Such potential adverse consequences are serious and multiple: discrimination, dissemination without consent of the results of medical genetic testing (which describe the patient’s human source code), and the significant fear associated with such consequences that may lead patients to forego potentially lifesaving testing.

33. Medical genetic testing can be a matter of life or death. The presence of a valid object of the criminal law, combined with prohibitions and penalties, renders the *GND*A’s prohibitions a constitutional exercise of federal jurisdiction under s. 91(27) of the *Constitution Act, 1867*.

### **PART IV - COSTS**

34. CCMG asks that that no costs be awarded to or against it.

**ALL OF WHICH IS RESPECTFULLY SUBMITTED** this 4th day of July, 2019.




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Michael Bookman

<sup>21</sup> See *Rodriguez v. British Columbia*, [1993] 3 SCR 519, [**Rodriguez**], p. 595; *R. v. Morgentaler*, [1988] 1 S.C.R. 30, [**Morgentaler**], p. 74-75.

<sup>22</sup> *Reference Re Assisted Human Reproduction Act*, para. 58.

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### **Legislative Provisions**

<i>Genetic Non-Discrimination Act</i> , <b><u>SC 2017, c 3</u></b>	
<i>Loi sur la non-discrimination génétique</i> , <b><u>LC 2017, c 3</u></b>	