

# Life Insurers' Access to Genetic Information: A Way Out of the Stalemate?

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## Introduction

The advent of genomics at the end of the 20th century intensified the existing debate surrounding the social, ethical, and legal issues raised by modern medicine. Genetics increased popular awareness of fundamentally important issues including the redefinition of the human being, eugenics and the organization of healthcare in liberal democracies. The general population, informed through the lens of the media, had to quickly learn and understand the meaning of complex terms and concepts such as “cloning”, “genetic discrimination”, “stem cells”, “gene therapy”, or “medically assisted reproduction”.

The societal consequences of scientific developments in the field of genomics were especially visible in the areas of privacy and personal confidentiality. In the mid-1980s, progress in the development of predictive tests for Huntington's disease coincided with the first discussions in specialized fields about the risks of “genetic discrimination.”<sup>1</sup> The emerging debate, polarized by the media, became more extensive during the 1990s. Insurers' uncompromising attitude,<sup>2</sup> and the growing concern of the population about the vast possibilities presented by genetics, drove political decision-makers in many countries to legislate in order to address popular concerns.<sup>3</sup>

However, despite intensive regulatory activity in Europe and in the United States, the socio-ethical debate on insurance and genetics has barely progressed during the last twenty years. After focussing on certain aspects of the

genetics and insurance dilemma, this article will provide a critical analysis of the evolution of the debate in France and Canada.<sup>4</sup> Finally, the author will argue for the need to redefine the dialogue by broadening its scope, adopting a long term perspective and recognizing the need for transparency in order to exit the dead-end we are currently facing. In the current context, genetics could well be hiding a more fundamental debate about the place of insurance in the contemporary democratic state.

## Characteristics of the Debate

The results of two recent North American surveys highlight the general discomfort caused by the fact that insurers could potentially use genetic information for underwriting purposes.<sup>5</sup> However, the two surveys share the same difficulty with regard to defining and circumscribing the precise extent of the popular sentiment. The first shows that although the majority of individuals surveyed oppose insurance companies' access to genetic data, these same individuals still perceive genetic information as being similar to other types of medical information and cannot articulate why it should be treated differently.<sup>6</sup> Although the results of the second study show a certain concern in the population *vis-à-vis* genetic discrimination, this concern seems to have had only a marginal influence on the surveyed population's decision to undergo genetic testing or not.<sup>7</sup> The discomfort reflected in these and other studies<sup>8</sup> could be explained by the difficulty of defining the concept of “genetic discrimination”.



The concept of discrimination evokes a different reality for insurers, policy-makers, and the general population. Therefore, a single question about genetic discrimination may be perceived differently by various audiences.<sup>9</sup> For example, in order to assess if a given law or governmental practice is discriminatory or not, the Canadian judiciary will follow article 15(1) of the *Canadian Charter of Rights and Freedom*<sup>10</sup> and the corresponding case law. In this situation, discrimination is used to indicate a type of distinction that is both unjustified and based on prohibited (or analogous) grounds, i.e., unlawful discrimination. On the other hand, for an insurer, the selection and classification of life insurance applicants based on health factors and risk level is perceived as a kind of discrimination that is both rational and legal, i.e. actuarial discrimination.<sup>11</sup> Finally, for the general population, any type of distinction between individuals, regardless of the justification, will likely be considered discriminatory especially if it results in unfavourable treatment.<sup>12</sup>

Adding the term “genetic” before the word “discrimination” will then exponentially increase the complexity of the expression. First, in the interest of clarity, we ought to define what genetic discrimination means: discrimination based on genetic tests results, genetic information, genetic heritage, connection to a genetically defined population group or, more broadly, all of the above. Then, it is necessary to assess what kind of medical information should be considered as genetic. Considering that an increasingly large number of pathologies have been found to have genetic components, this could be a very challenging undertaking.

Recent publications on these subjects demonstrates the inadequacy of approaches based on a broad prohibition of genetic discrimination in insurance,<sup>13</sup> even though this approach is used in numerous legal texts<sup>14</sup> and normative documents.<sup>15</sup> Assuming that it would be possible to arrive at an optimal definition of what constitutes genetic information (and genetic tests), we must question the relevance of distinguishing it from other types of medical information and granting it distinct and separate protection. The advocates of genetic exceptionalism (a position that considers

genetic information as different from other types of health information and warranting special treatment) have advanced various reasons in support of their position. For example, the predictive aspect and familial or populational nature of genetic information, the particularly revealing nature of DNA, and the unreliability of genetic results, etc.<sup>16</sup> Opponents, on the other hand, point out that the majority of elements invoked to justify genetic exceptionalism are not unique to genetic information and could also apply to other types of medical information. According to them, genetic exceptionalism is due to a social perception rather than a proven scientific reality.<sup>17</sup> The debate about the relevance of genetic exceptionalism, like the one about genetics and insurance, remains currently unresolved.

Finally, in countries with a universal healthcare system, the population no longer perceives life insurance as a simple “commercial product” allowing individuals to procure benefits in addition to those provided to the collectivity by the State.<sup>18</sup> This new perception may be due to the quasi-necessity, nowadays,

of having life insurance in order to obtain certain goods considered essential to modern life, such as a house or a car. In these countries, access to a basic level of life insurance seems to be considered by many as a social necessity rather than an option for the privileged few who have sufficient financial resources.<sup>19</sup>

## France

The debate concerning the use of genetic information by French insurers for underwriting purposes began relatively early. Already in 1991, the National Consultative Ethics Committee [CCNE] recommended in its *Opinion n°25* that insurance companies be prohibited from accessing information contained in genetic databanks or to request this information from the insurance applicants.<sup>20</sup>

Three years later, the *Loi n°94-653 du 29 juillet 1994* was enacted to limit insurers’ freedom of action. This law stipulates that “the genetic study of a person’s characteristics cannot be undertaken except for medical or scientific

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research purposes” and that “the consent of the individual must be obtained before the study is conducted”.<sup>21</sup> That same year, French insurers adopted a five year moratorium, pledging not to take into account the results of genetic tests conducted on insurance applicants, even if the individuals provided this information voluntarily.<sup>22</sup>

The cautious attitude of the French legislature, the insurance industry, and geneticists was, however, not sufficient to alleviate tensions.<sup>23</sup> In the European context, where many countries had already legislated in this area,<sup>24</sup> the expectations and mistrust towards insurers were high. The following excerpt from CCNE’s *Opinion n°46* illustrates the position of both the scientific community and a significant portion of the French population at the time:

Genetic tests give information on the identity of persons and emphasise their diversity which contributes to the rich nature of humankind. To use such information for the purpose of selection or of discrimination in social or economic terms, be that in the realm of public health policies, employment, or insurance systems, would be crossing a boundary of the most extreme gravity and would question those principles of equality of rights, dignity and solidarity for all human beings upon which society as we know it is based. The CCNE insists on the necessity of observing those fundamental principles whatever aims may be pursued by genetic testing. Human Rights are at stake.<sup>25</sup>

France was one of the original signatories of the *Convention on Human Rights and Biomedicine* in 1997. This seminal European *Convention* prohibits both genetic discrimination and the use of genetic information outside the medical or research contexts.<sup>26</sup> Prior to ratification, each state is expected to bring its laws in conformity with the *Convention*. This may necessitate a change in legislation or even the adoption of a new law. Such legislation must include legal sanctions as well as provisions for the individuals who have suffered undue harm caused by contravening entities.<sup>27</sup> Although France has as yet to ratify the *Convention*, the influence it had on the French approach to the genetics and insurance debate is undeniable.

In the late 1990s, the differences between the French government, the scientific community, and the French population on one side, and the insurance professionals on the other, seemed irreconcilable. For example, despite the

renewal of the five year moratorium by French insurers in April 1999, the French *Conseil d’État* recommended to the government to “adopt a strict framework concerning the communication of [genetic test] results to third parties”,<sup>28</sup> specifying that “the sensitivity of genetic data justifies prohibiting insurers from requesting that insurance candidates undergo genetic tests before the conclusion of a contract”.<sup>29</sup>

The conclusion of the debate was foreseeable: With the *Loi no 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé*, the French government formally prohibited the use of genetic information by insurers. Pursuant to this law, “[n]o one can be made the object of discrimination because of his or her genetic characteristics”.<sup>30</sup> Moreover, insurers can no longer take into account the results of an insurance applicant’s genetic exams, even if the applicant submits them voluntarily. Finally, insurers cannot ask any questions regarding genetic tests and their results, nor can they request that an individual undergo genetic testing before an insurance contract is concluded or during the full course of the contract.<sup>31</sup>

The French legislature’s decision appears premature for various reasons. First, this legislative policy does not take into account the impact that such a broad prohibition on the use of genetic test results and other information on the genetic “characteristics” of insurance applicants will have on the French insurance industry. To date, no large-scale empirical study has been carried out regarding the negative consequences (e.g. adverse-selection) that could accompany this type of prohibition. The conclusions of empirical studies and actuarial models developed in relation to this topic have a limited applicability.<sup>32</sup> Second, the prohibition against discrimination based on “genetic characteristics”, as we demonstrated earlier, could have significant impact given the blurred definitions of the terms “discrimination”, “genetic”, and even “characteristics”. Since a large proportion of all modern pathologies have genetic components,<sup>33</sup> a broad interpretation of this law could prevent insurers from using most medical information for the evaluation of risk in insurance contracts. Finally, by treating genetic information differently from other types of medical information, doesn’t the French legislature risk reinforcing genetic exceptionalism and effectively increasing the social stigmatization of at-risk individuals? It is worth noting that this group will become more and more numerous with the progress of genetics.<sup>34</sup>



## Canada

The debate over insurance and genetics in Canada took place in a significantly different context than in France. First of all, Canada has a federal system in which the Constitution grants exclusive legislative authority to the federal and provincial governments over their respective areas of responsibility. As life insurance falls under provincial jurisdiction, the federal government cannot directly legislate on this topic. Second, Canadian discussions about insurance and genetics have been influenced, and even obscured, by the prevailing situation in the United States,<sup>35</sup> despite differences in the issues at stake.<sup>36</sup> These two factors, as well as the limited interest in the debate shown by the general population and Canadian lobby groups,<sup>37</sup> have resulted in the near immobilization of both levels of government on this issue.

Provincial insurance laws do not specifically protect the personal genetic information of Canadian consumers. According to the *Uniform Insurance Act* and the *Quebec Civil Code*, insurance applicants must declare all known facts that could materially influence an insurer's risk assessment. Failing to do so could lead to the nullification of their insurance contract.<sup>38</sup> This sanction is applicable even if there is no link between the insured individual's false declarations and his or her cause of death.<sup>39</sup> Moreover, contractual freedom could be invoked by insurance companies to require genetic testing as a precondition to the conclusion of an insurance contract. However, the Canadian Life and Health Insurance Association Inc. has advised its members against adopting this kind of practice.<sup>40</sup> Privacy protection and human rights legislation as applied in Canada does not effectively counterbalance the lack of consumer protection in Canadian insurance laws. Federal and provincial privacy laws generally allow third-party access to personal information, with the consent of the individual who is the subject of the information.<sup>41</sup> It has therefore become common practice for insurers to request that applicants consent, on the insurance application form, to having any representation they made concerning their health status, along with their medi-

cal history, verified by a representative of the insurer.<sup>42</sup> Human rights legislation and Charter provisions prohibiting discriminatory practices could theoretically offer some degree of protection to insurance applicants.<sup>43</sup> However, considering the absence of any specific prohibition against genetic discrimination and the absence of clear legal precedents, the actual impact of the Charter on the problem of genetics and life insurance remains to be determined.<sup>44</sup>

Yet, the Canadian debate on life insurance and genetics began relatively early. In 1991, in a study paper on human dignity and genetics commissioned by the Canadian Law Reform Commission, legal scholar Bartha Knoppers suggested that "the very nature of private insurance legitimates discrimination"<sup>45</sup> and that while waiting for genetic education to be ensured at all levels of society, "we may need a specific legal prohibition on genetic discrimination."<sup>46</sup> In 1995, the Privacy Commissioner of Canada suggested in a report on genetic testing and privacy, that if the insurers' decision to use bio-

technology to their advantage seems logical at the individual level, it does not at the societal level, nor is it necessarily humane.<sup>47</sup> Finally, during the last ten years, reports from different Canadian advisory bodies have recommended that insurers adopt a moratorium or that governments legislate with regard to the use of genetic tests for life insurance underwriting purposes.<sup>48</sup> For example, Ontario's Provincial Advisory Committee on New Predictive Genetic Technologies recommended that:

The government should consider implementing a moratorium that would prevent insurance companies...from using genetic information to determine eligibility for insurance...A moratorium would provide time for the government to consult and work with interested stakeholders to develop policies and practices for...the insurance industry using genetic information. The moratorium should remain in effect until proper policies and processes for the use of genetic information in these contexts are implemented.<sup>49</sup>

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These warnings unfortunately did not influence the practice of Canadian insurers. In 2000, the Canadian Life and Health Insurance Association Inc., which represents the major part of the industry, adopted a reference text for its members, stating that, in the event that a genetic test had already been performed and the insurance applicant or his/her doctor had had access to the results, it was natural that the insurer seek to obtain the information just as he would other elements of the applicant's health history.<sup>50</sup> The Canadian Institute of Actuaries and the Canadian Life Insurance Medical Officers Association adopted similar policies in 2000<sup>51</sup> and in 2002.<sup>52</sup>

During 2003, aware of the deadlock over the question of access to genetic information by insurers, representatives from patient groups, researchers (in ethics, law, and medicine), physicians, and insurers met in order to create a working group on genetics and life insurance in order to move the debate forward.<sup>53</sup> After two meetings, the working group produced a reflection paper which recognized the "need to discuss" two potential solutions to the debate. The solutions identified were the following: 1) the adoption of a moratorium on the use of genetic tests by insurers, and 2) the evaluation of the validity of genetic tests and the management of customer complaints by an independent consulting committee.<sup>54</sup> Unfortunately, the absence of a strong joint position and the lack of governmental interest in this endeavor limited the success of this initiative and bodes ill for the Canadian debate. Canadian researchers and clinicians now worry that the Canadian population will have to face the negative effects of insurers' intransigence and the government's indifference.<sup>55</sup>

## Conclusion

On multiple occasions, UNESCO has reiterated the importance of the protection from discrimination based on genetic data<sup>56</sup> or genetic characteristics.<sup>57</sup> Governments and insurers from over 40 countries in three different continents (North America, Europe, and Asia) have now decided to adopt either moratoria (as in the United Kingdom, Germany, Ireland, etc.) or laws (as in France, Belgium, Israel, South Korea, etc.) to restrict the use of genetic information and tests by insurers.<sup>58</sup> The magnitude of the controversy does not, however, seem to have diminished as a result of these measures.<sup>59</sup>

Despite their completely different reactions and approaches to insurers' use of genetic information, France and Canada

have each arrived at a deadlock. France, by prematurely legislating and by neglecting the arguments of one of the parties to the debate (the insurers), has encouraged genetic exceptionalism and therefore, ironically, heightened the need to distinguish genetic information from other types of medical information (which constitutes a form of discrimination in itself). Canada, because of the inaction of the principal stakeholders (namely, government and insurers) is now one of the only developed countries that does not offer its citizens any specific protection against the risks of genetic discrimination. In these two countries, a profound questioning as well as a frank and open dialogue between all involved parties have become necessary.

In countries with a universal healthcare system, life insurance remains a private contract. Insurance companies have an understandable desire to remain profitable and competitive by offering the lowest possible rates to their customers. For insurers, it seems entirely natural to use the best possible tools in their evaluation of applicants' risk levels. It seems difficult and somewhat illogical to defend a policy prohibiting insurers from using genetic information while permitting them to use other types of medical information, such as family history (which, incidentally, contains much genetic information). In fact, it seems unwarranted to impose on insurers and ultimately, on society, the financial cost of a growing number of diseases with genetic components. The governments of the states concerned must also involve themselves financially in this debate and share with the population some of the economic burden of what has become perceived as a social necessity (e.g. by offering a publicly funded minimum life insurance protection to its citizens or by subsidizing the life insurance industry for ignoring relevant actuarial information).

Isn't the omnipresence of genetic exceptionalism in many developed countries really a manifestation of a more profound discomfort about access to healthcare and about the protection and management of sick or at-risk individuals? A constructive debate about genetics and insurance, rather than being undertaken from a "genocentric" perspective, should take place within a wide-ranging social debate about the place of the welfare state in the 21st century. While waiting for the beginning of such a broad debate, given the limited number of genetic tests that are considered scientifically valid, reliable and relevant for insurers, the adoption of moratoria on the use of predictive genetic tests in life insurance seems to be a prudent solution that would be relatively un-constraining for insurers.



## Acknowledgements

I would like to thank Mireille Lacroix and Guillaume Sillon for editorial assistance along with many useful comments on the manuscript. I am also grateful to Alexandra Saginur for her contribution to the English translation of the manuscript. I wish to acknowledge the financial contribution of the Canadian Institutes of Health Research (CIHR) for the INHERIT BRCA's project.

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1. Gina Kolata, "Genetic Screening Raises Questions for Employers and Insurers" (1986) 232:4748 *Science* 317.
2. Ine Van Hoyweghen, Klasien Horstman & Rita Schepers, "'Genetics is not the issue': Insurers on Genetics and Insurance" (2005) 24:1 *New Genetics and Society* 79 at 82.
3. Trudo Lemmens, Yann Joly & Bartha M. Knoppers, "Genetics and Life Insurance: A Comparative Analysis" (2004) 2:2 *GenEdit* 1, online: *HumGen International* <[http://www.humgen.umontreal.ca/int/GE\\_Arch\\_v.cfm?an=2004&no=2&lang=1](http://www.humgen.umontreal.ca/int/GE_Arch_v.cfm?an=2004&no=2&lang=1)>.
4. These two countries were selected because they illustrate two radically different social, ethical and legal perspectives on access to genetic information by life insurers.
5. Canada, *Public Opinion Research Into Genetic Privacy Issues* (Ottawa: Pollara Research and Earncliffe Research and Communications, 2003) at 11 [Canada], online: *Biostrategy* <<http://www.biostrategy.gc.ca/english/View.asp?pmiid=524&x=545>>; Mark A. Hall *et al.*, "Concerns in a Primary Care Population About Genetic Discrimination by Insurers" (2005) 7:5 *Genetic Medicine* 311 at 311 [Mark A. Hall *et al.*].
6. Canada, *ibid.* at 9.
7. Mark A. Hall *et al.*, *supra* note 5 at 313.
8. Dorothy C. Wertz, "'Genetic Discrimination': Result of a Survey of Genetics Professionals, Primary Care Physicians, Patients and Public" (1998/99) 7 *Health L. Rev.* 7; Mark A. Hall & Stephen S. Rich, "Patients' Fear of Genetic Discrimination by Health Insurers: The Impact of Legal Protections" (2000) 2:4 *Genetic Medicine* 214.
9. Mark A. Rothstein & Mary R. Anderlik, "What is Genetic Discrimination, and When and How can it be Prevented?" (2001) 3:5 *Genetic Medicine* 354 at 354.
10. *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 ("15. (1) [Equality before and under law and equal protection and benefit of law] Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. ").
11. *Supra* note 9 at 354.
12. Margaret F. Otlowski, Sandra D. Taylor & Kristine K. Barlow-Stewart, "Genetic Discrimination: Too Few Data" (2003) 11 *European Journal of Human Genetics* 1.
13. Amy Otchet "Forsaking Genetic Secrets" *The Unesco Courier* (March 2001) 29, online: UNESDOC <<http://unesdoc.unesco.org/images/0012/001221/122144e.pdf#122158>>.
14. See for example Estonia, *Human Genes Research Act*, 2000, online: Estonian Legal Language Centre <<http://www.legaltext.ee/text/en/X50010.htm>>; France, *Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé*, J.O n° 54, 5 mars 2002, 4118.
15. United Nations Educational, Scientific and Cultural Organization (UNESCO), International Bioethics Committee (IBC), *Universal Declaration on the Human Genome and Human Rights*, 1997, online: UNESCO <<http://unesdoc.unesco.org/images/0011/001102/110220e.pdf#page=47>>; World Medical Association (WMA), "The World Medical Association Statement on Genetics and Medicine" 2005, online: World Medical Association <<http://www.wma.net/e/policy/g11.htm>> JAVASCRIPT:openP('http://www.wma.net');
16. See among others, Thomas Murray, "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?" in Mark A. Rothstein, ed., *Genetic secrets: protecting privacy and confidentiality in the genetic era* (New Haven and London: Yale University Press, 1997) at 60; Patricia Kosseim, Martin Letendre & Bartha M. Knoppers, "Protecting Genetic Information: A Comparison of Normative Approaches" (2004) 2:1 *GenEdit* 1 [Patricia Kosseim], online:



- HumGen International  
<[http://www.humgen.umontreal.ca/int/GE\\_Arch\\_v.cfm](http://www.humgen.umontreal.ca/int/GE_Arch_v.cfm)>.
17. Patricia Kosseim, *ibid.*; Mark A. Rothstein, "Genetic exceptionalism and legislative pragmatism" (2005) 35 *The Hastings Center Report* 27.
  18. Nuffield Council on Bioethics, *Genetics and Human Behaviour: The Ethical Context* (October, 2002) at 185, online: Nuffield Council on Bioethics <<http://www.nuffieldbioethics.org/fileLibrary/pdf/nuffieldgeneticsrep.pdf>>; Bartha M. Knoppers, Béatrice Godard & Yann Joly, "A Comparative International Overview" in Mark A. Rothstein, ed., *Genetics and Life Insurance: Medical Underwriting and Social Policy* (Cambridge and London: MIT Press, 2004) 173 [Bartha M. Knoppers].
  19. Tony McGleenan & Urban Wiesing, "Insurance and Genetics: European Policy Options" (2000) 7 *Euro. J. Health L.* 367 at 369, 374.
  20. National Consultative Ethics Committee, *Opinion N°25 regarding the application of genetic testing to individual studies, family studies and population studies* (1991) at 4, online: Comité Consultatif National d'Éthique <[http://www.ccne-ethique.fr/english/avis/a\\_025.htm#deb](http://www.ccne-ethique.fr/english/avis/a_025.htm#deb)>.
  21. France, *Loi n° 94-653 du 29 juillet 1994 relative au respect du corps humain*, J.O n°175, 30 juillet 1994, 11056 [translated by author].
  22. Fédération Française des Sociétés d'Assurances, *Étude génétique des caractéristiques d'une personne. L'engagement des assureurs de la FFSA* (1994).
  23. See for example Martine Bulard, "Vers une sélection génétique des assurés" (juin 1999) *L'usine nouvelle Biotech* 26; Marie-Louise Briard, "Encadrement de la génétique en France" (2001) 34 *Actualité et dossier en santé publique* 38, online: Haut Comité de la santé publique <<http://hcsp.ensp.fr/hcspi/docspdf/adsp/adsp-34/ad343844.pdf>>.
  24. *Supra* note 3; see also Council of Europe, *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*, 1997 [Council of Europe], online: Council of Europe <<http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>>.
  25. National Consultative Ethics Committee, *Opinion N°46 — Opinion and recommendations on "Genetics and medicine: from prediction to prevention"* (1995) at 7, online: Comité Consultatif National d'Éthique <[http://www.ccne-ethique.fr/english/avis/a\\_046.htm#deb\\_](http://www.ccne-ethique.fr/english/avis/a_046.htm#deb_)>.
  26. Council of Europe, *supra* note 24 at 4.
  27. *Supra* note 3 at 4.
  28. France, Conseil d'État, *Les lois de bioéthique: 5 ans après*, Rapport du Conseil d'État (November 25, 1999) at 123 [translated by author].
  29. *Ibid.* at 124 [translated by author].
  30. France, *Loi n° 2002-303 du 4 mars 2002*, *supra* note 14 at 3 [translated by author].
  31. *Ibid.* at 56.
  32. As an example of empirical studies, see Cathleen D. Zick *et al.*, "Genetic Testing for Alzheimer's Disease And Its Impact on Insurance Purchasing Behaviour" (2005) 24:2 *Health Affairs* 483; as an example of actuarial models, see Angus S. MacDonald, "Moratoria on the Use of Genetic Tests and Family History for Mortgage-Related Life Insurance" (2003) 9 *British Actuarial Journal* 217.
  33. The International HapMap Consortium, "The International HapMap Project" (2003) 426:6968 *Nature* 789.
  34. Bartha M. Knoppers, *supra* note 18.
  35. A vast majority of American states have legislated to prohibit genetic discrimination in the health and long term insurance sectors. However, the American legislator has thus far paid little attention to the life insurance sector and issues in this field have only been debated within the academic community. The context is also different because in the United States, health care is delivered principally by private professionals and in private institutions. Even though some health care financing programs exist at the federal, state, and local level, a large number of American citizens must still pay for health care, without support from a third party payment source. See Barry R. Furrow *et al.*, *International Encyclopedia of Laws, Medical Law* (United States: Kluwer Law International, 2002) at 22.
  36. See for example Pauline Gravel, "Assurance, la discrimination génétique existe" *Le Devoir* (10 September 2002), online: *Le Devoir* <<http://www.ledevoir.com/2002/09/10/8866.html>>.
  37. *Supra* note 5 at 5.
  38. *Insurance Act*, R.S.B.C. 1996, c. 226, s. 41(1); *Insurance Act*, C.C.S.M. 1987, c. 140, s. 160(1); *Insurance Act*, R.S.N.B. 1973, c. I-12, s. 144; *Insurance Act*, R.S.A. 2000, c. I-3, s. 567(1); *Insurance Act*, R.S.N.S. 1989, c. 231, s. 185(1); *Insurance Act*, R.S.P.E.I. 1988, c. I-4, s. 131(1); *Insurance Act*, R.S.S. 1979, c. S-26, s. 145(1); *Insurance Act*, R.S.N.W.T. 1988, c. I-4, s. 81(1); *Insurance Act*, R.S.Y. 1986, c. 91, s. 85(1); *Life Insurance Act*, R.S.N. 1990, c. L-14, s.



- 14(1); *Insurance Act*, R.S.O. 1990, c. I-18, s. 183(1); Art. 2408 C.c.Q.
39. *Insurance Act*, R.S.B.C. 1996, c. 226, s. 41(2); *Insurance Act*, C.C.S.M., c. 140, s. 160(2); *Insurance Act*, R.S.N.B. 1973, c. I-12, s. 144 (2), 202(2); *Insurance Act*, R.S.A. 2000, c. I-3, s. 567(2); *Insurance Act*, R.S.N.S. 1989, c. 231, s. 185(2), 82(2); *Insurance Act*, R.S.P.E.I. 1988, c. I-4, s. 131(2), 191(2); *Insurance Act*, R.S.S. 1979, c. S-26, s. 145(2), 242(2); *Insurance Act*, R.S.N.W.T. 1988, c. I-4, s. 81(2), 185(2); *Insurance Act*, R.S.Y. 1986, c. 91, s. 85(2), 188(2); *Life Insurance Act*, R.S.N. 1990, c. L-14, s. 14(2), 20(2); *Insurance Act*, R.S.O. 1990, c. I-18, s. 183(2) 308(2); Art. 2410 C.c.Q.
40. Canadian Life and Health Insurance Association Inc., *Reference Document: Genetic Testing: Industry Position 2000* (updated January 1, 2003) at 1, online: Canadian Life and Health Insurance Association <[http://www.clhia.ca/download/genetic\\_testing\\_ind\\_posn.pdf](http://www.clhia.ca/download/genetic_testing_ind_posn.pdf)>.
41. Yann Joly, “Commentary: insurance companies should abandon their defensive approach” (2005) 25 *The Lawyers Weekly* 14.
42. Canadian Life and Health Insurance Association Inc., *A Guide to Life Insurance* (2002) at 19.
43. *Supra* note 10.
44. On this topic see Trudo Lemmens, “Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Developments and Canadian Options” (2003) *Health L. J.* 41 (Special Edition — Health Law in the 21st Century).
45. Law Reform Commission of Canada, *Human dignity and genetic heritage* by Bartha M. Knoppers (Ottawa: Law Reform Commission of Canada, 1991) at 50.
46. *Ibid.*
47. The Privacy Commissioner of Canada, *Genetic Testing and Privacy* (1995), online: Privacy Commissioner <[http://www.privcom.gc.ca/information/ar/02\\_04\\_03\\_e.asp](http://www.privcom.gc.ca/information/ar/02_04_03_e.asp)>.
48. See for example Ontario, Law Reform Commission, *Report on genetic testing* (Toronto: Ontario Law Reform Commission, 1996) at 126; Québec, Ministry of Research, Science & Technology, Commission de l'éthique de la science et de la technologie, *The Ethical Issues of Genetic Databases: Towards Democratic and Responsible Regulation — Position Statement* (February, 2003) at xviii.
49. The Provincial Advisory Committee on New Predictive Genetic Technologies, *Genetic Services in Ontario: Mapping the Future* (2001) at 27, online: Ontario Ministry of Health and Long-Term Care <[http://www.health.gov.on.ca/english/public/pub/ministry\\_reports/geneticsrep01/genetic\\_report.pdf](http://www.health.gov.on.ca/english/public/pub/ministry_reports/geneticsrep01/genetic_report.pdf)>.
50. *Supra* note 40 at 1.
51. Canadian Institute of Actuaries, *Statement on Genetic Testing and Insurance* (2000).
52. Canadian Life Insurance Medical Officers Association, *CLIMOA Guidelines on Genetic Testing* (2002).
53. Bartha M. Knoppers *et al.*, “Genetics and Life Insurance in Canada: Points to Consider” (2004) 170:9 *Canadian Medical Association Journal* 1421 at online 1, online: Canadian Medical Association Journal <<http://www.cmaj.ca/cgi/data/170/9/1421/DC2/1>>.
54. *Ibid.* at 3.
55. “L’assurance vie et les tests génétiques” *Enjeux* [Television Program, Radio-Canada] (November 23, 2004), online: <[http://www.radio-canada.ca/actualite/v2/enjeux/niveau2\\_1286.shtml](http://www.radio-canada.ca/actualite/v2/enjeux/niveau2_1286.shtml)>.
56. United Nations Educational, Scientific and Cultural Organization (UNESCO), International Bioethics Committee (IBC), *International Declaration on Human Genetic Data*, 2003, online: UNESCO <[http://portal.unesco.org/en/ev.php-URL\\_ID=17720&URL\\_DO=D0\\_TOPIC&URL\\_SECTION=201.html](http://portal.unesco.org/en/ev.php-URL_ID=17720&URL_DO=D0_TOPIC&URL_SECTION=201.html)>.
57. *Supra* note 15 at 41.
58. *Supra* note 3.
59. *Supra* note 13.

