

# Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Developments and Canadian Options.

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## Introduction

In June 2002, in the context of a major biotechnology conference in Toronto, the *Ottawa Citizen* reported that Ms. Hope, a Vice-President of the Canadian Life and Health Insurance Association, declared that for life insurance contracts, insurers would deny the claims of people who undergo genetic testing and fail to inform their insurer of the results, even if the insurance forms do not ask explicitly for them.<sup>1</sup> The statement created a short public stir over the potential insurance implications of the new genetics. The CEO of the Canadian Cancer Society, Julie White, in a widely distributed letter criticized as “irresponsible and indefensible” the stance of the insurance industry.<sup>2</sup> Mark R. Daniels, the President of the Canadian Life and Health Insurance Association Inc., responded with a letter in which he outlined the industry’s approach towards genetic testing and suggested the quote from the *Ottawa Citizen* was untrue.<sup>3</sup> But while Daniels’ letter confirms the insurance truism that people who already have life insurance and subsequently undergo genetic testing do not have to divulge their results, it also confirms one interpretation of Ms. Hope’s statement to the *Ottawa Citizen*. Ms. Hope had allegedly stated that “if an applicant has had genetic testing done, failure to provide relevant information, in the context of applying for life insurance, could render the contract void.”<sup>4</sup> The report in the *Ottawa Citizen* was perhaps a little unclear, because it could be interpreted as implying that someone who already has insurance has a duty to report new test results. This is indeed incorrect, since, as I shall discuss further below, in life insurance contracts a duty to disclose risk factors exists only at the time of the conclusion of the contract. But Ms. Hope and Mr. Daniels both confirm without qualification that in the industry’s view, genetic test results have to be disclosed at the time of the conclusion of the contract.

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<sup>1</sup> S. Staples “Insurers Won’t Pay Clients Who Keep Genetic Secrets” *The Ottawa Citizen* (11 June 2002) A1.

<sup>2</sup> Letter from Julie White to Mark R. Daniels (9 July 2002).

<sup>3</sup> Letter from Mark R. Daniels to Julie White (9 July 2002).

<sup>4</sup> *Ibid.*

This exchange about the extent of the duty to disclose genetic test results is a relatively rare indication of a tension that will likely only increase around the use of genetics for life insurance purposes. For some time, several authors, including myself,<sup>5</sup> have predicted that as genetic testing becomes more prevalent and affordable, insurers will be tempted to use it. The large investments in the development of genetic testing will contribute to the promotion and marketing of such tests. Jon Beckwith and Joseph S. Alper anticipate that an increase in the number of tests will result in a growing number of uninsurable people.<sup>6</sup> Sonia Suter, while acknowledging that the future of insurers' use of genetics remains uncertain, states that "[a]s our understanding about the clinical significance of various disease genes increases, genetic tests will improve and become more prevalent and cost-effective."<sup>7</sup> She rightly points out that the actuarial value of this information will likely be exaggerated by the media and misunderstood by the public, but that does not mean the tests will not be used. As she further mentions, "evidence shows that insurers and employers are careless and imprecise in their use of other actuarial data and risk information."<sup>8</sup> Aggressive marketing of tests, based on – or combined with – preliminary scientific data that allow for speculative associations between increased health risks and specific genetic mutations, could very well make genetics into an attractive tool for insurers. Moreover, as Clayton points out, "insurers, fearful of adverse selection, have repeatedly stated that they want to know whatever those they insured know."<sup>9</sup>

While Canadian insurers have remained largely silent on this topic, the public exchange may be an indication of the insurance industry's awareness that the debate can no longer be avoided. One could suggest the long-standing "wait-and-see" position of the industry is coming to an end and it is sending messages, perhaps to make the public gradually accustomed to the fact industry will start using this new technology or at least the information resulting from the health care applications of genetics.

It therefore becomes more important than ever in Canada to consider various regulatory, policy and legislative options to deal with the genetics divide that could be created by third party use of increasingly detailed genetic information. In this paper, I want to sketch various options that have been employed in other countries to deal with the use of genetics in insurance and to highlight those that seem promising in the Canadian context.

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<sup>5</sup> See Trudo Lemmens, "Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?" (2000) 45 McGill L.J. 347 ["Selective Justice"].

<sup>6</sup> Jon Beckwith & Joseph S. Alper, "Reconsidering Genetic Anti-Discrimination Legislation" (1998) 26 J.L. Med. & Ethics 205.

<sup>7</sup> Sonia M. Suter, "The Allure and Peril of Genetic Exceptionalism: Do We Need Special Genetics Legislation?" (2001) 79 Washington U.L.Q. 669 at 681.

<sup>8</sup> *Ibid.* at 713.

<sup>9</sup> Ellen Wright Clayton, "Comments on Philip R. Reilly's 'Genetic Discrimination'" in Clarissa Long, ed., *Genetic Testing and the Use of Information* (Washington: American Enterprise Institute Press, 1999) 134 at 135.

In order to situate these options, it is important to discuss briefly the legal context in which the debate on genetics and insurance plays out and to reiterate why the potential uses of genetics in insurance raise concerns.<sup>10</sup>

## A. Current Canadian Legal Framework

### 1. Canadian Insurance Law and Genetics<sup>11</sup>

Insurance can be defined as “a private contract in which one party, the insured, transfers certain risks of loss to another, the insurer, for monetary considerations.”<sup>12</sup> An insurance contract, then, “constitutes a binding obligation to pay or perform upon the happening of a specified contingency.”<sup>13</sup> Three essential elements of an insurance contract can be distilled from these definitions: (1) a premium; (2) compensation or monetary consideration; and (3) risk.

Insurance contracts contain a promise by an insurer to pay out specific amounts of compensation to premium payers in case of specified events. In theory, any risk can be covered by insurance. The most typical events are disease, physical impairment, unemployment, death, natural disaster, fire, or some other “act of God.” In this article, I shall focus on one of the traditional and most typical insurance contracts: life insurance.

The potential obligation to disclose genetic information, and the right of insurers to ask about that information, flows from the fact that “risk” is a crucial aspect of a private insurance contract. As François Ewald posits, “[w]ithout [risk], insurance would not be possible.”<sup>14</sup> Risk assessment through an underwriting process is key for determining whether insurers want to offer insurance coverage and at what price. Because knowledge about personal health risks is to a large degree within the control of insurance applicants,<sup>15</sup> applicants for insurance have a duty to declare all information that is material to the risk. This duty is qualified in both the *Uniform Insurance Act* and the *Quebec Civil Code* as an obligation *uberimae fidei*. The *Uniform Insurance Act* provides the following :

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<sup>10</sup>For a more detailed analysis of these concerns, see Lemmens, “Selective Justice”, *supra* note 5 at 369-383.

<sup>11</sup>The following discussion is based on Trudo Lemmens, *Genetic Information and Insurance: A Contextual Analysis of Regulatory Means of Promoting Just Distributions* (D.C.L. Thesis, McGill University, 2003) [unpublished] [*Genetic Information and Insurance*], in particular c. 4, 7. These two chapters are being prepared for publication as journal articles.

<sup>12</sup>*Black's Law Dictionary*, 6<sup>th</sup> ed., s.v. “insurance”.

<sup>13</sup>Donald Norwood & John P. Weir, *Norwood on Life Insurance Law in Canada*, 2nd ed. (Toronto: Carswell, 1993) at 17.

<sup>14</sup>François Ewald, “Genetics, Insurance and Risk” in Tony McGleenan, Urban Wiesing & François Ewald, eds., *Genetics and Insurance* (Oxford: BIOS Scientific Publishers Ltd., 1999) 17 at 21.

<sup>15</sup>Patrice Deslauriers, “Le questionnaire d’assurance fait une autre victime: quelques réflexions suscitées par l’affaire *Ouellette*” (1994) 73 Can. Bar Rev. 57 at 58.

An applicant for insurance and a person whose life is to be insured shall each disclose to the insurer in the application, on a medical examination, if any, and in any written statements or answers furnished as evidence of insurability, every fact within the person's knowledge that is material to the insurance and is not so disclosed by the other.<sup>16</sup>

The obligation of utmost good faith that characterizes the insurance contract applies to both parties and entails disclosure obligations for both parties. But as Brown and Menezes point out, it is clear that "the greater burden of the obligation to disclose falls on the customer."<sup>17</sup> According to David Norwood and John Weir, "the party seeking to be insured must not only not misrepresent in what such party conveys to the insurer, but must not leave anything out of their representations which would be material to the risk."<sup>18</sup>

The duty of making true and full statements relates to facts that are (1) material to the risk; and (2) within the knowledge of the insurance applicants.<sup>19</sup> Interesting case law has developed around the interpretation of what is "material to the risk" and "within the knowledge of the insurance applicant."<sup>20</sup> Material information is information relevant to risk appreciation.<sup>21</sup> It influences insurers in deciding to issue policies and in determining the appropriate premium.<sup>22</sup> The test, as accepted by the Privy Council in *Mutual Life Insurance Co. v. Ontario Metal Products Co.*<sup>23</sup> is whether, "if the fact concealed had been disclosed, the insurers would have acted differently,"<sup>24</sup> either by changing the premium, declining the coverage, or by inquiring further about the risk. Two central questions must be asked. First, what would reasonable insurers accept as risk? Second, would certain facts make them change their minds as to the insurability of a risk? This does not

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<sup>16</sup> *Insurance Act*, R.S.A. 2000, c. I-3, s. 567(1) [A.I.A.]; *Insurance Act*, R.S.B.C. 1996, c. 226, s. 41(1) [B.C.I.A.]; *Insurance Act*, C.C.S.M., c. I40, s. 160(1) [M.I.A.]; *Insurance Act*, R.S.N.B. 1973, c. I-12, s. 144 [N.B.I.A.]; *Insurance Act*, R.S.N.S. 1989, c. 231, s. 185(1) [N.S.I.A.]; *Insurance Act*, R.S.P.E.I. 1988, c. I-4, s. 131(1) [P.E.I.I.A.]; *Saskatchewan Insurance Act*, R.S.S. 1979, c. S-26, s. 145(1) [S.I.A.]; *Insurance Act*, R.S.N.W.T. 1988, c. I-4, s. 81(1) [N.W.I.A.]; *Insurance Act*, R.S.Y. 1986, c. 91, s. 85(1) [Y.I.A.]; *Life Insurance Act*, R.S.N. 1990, c. L-14, s. 14(1) [N.F.L.I.A.]; *Insurance Act*, R.S.O. 1990, c. I-18, s. 183(1) [O.I.A.].

<sup>17</sup> Craig Brown & Julio Menezes, *Insurance Law in Canada*, vol. 1, looseleaf (Scarborough, Ont.: Carswell, 2001) at 1-5.

<sup>18</sup> Norwood & Wier, *supra* note 13 at 1175.

<sup>19</sup> *Ibid.* at 299; see also Brown & Menezes, *supra* note 17 at 5-2, who do not separate the issues so explicitly.

<sup>20</sup> A detailed analysis of the case law in the context of genetics exceeds the scope of this article, but is the subject of another forthcoming publication.

<sup>21</sup> *Beaulieu v. Industrielle, cie d'assurance sur la vie*, [1986] R.J.Q. 222 at 224 (C.S.), *aff'd* (1990) R.R.A. 172 (C.A.).

<sup>22</sup> *Mutual Life Assurance Company v. Bernier* (1967), [1968] B.R. 595 at 600; *Mutual Life Insurance Co. v. Ontario Metal Products Co.*, [1925] A.C. 344, [1925] 1 D.L.R. 583 at 588-589 (P.C.) [*Ontario Metal Products Co.* cited to D.L.R.], *aff'g Ontario Metal Products Co. v. Mutual Life Insurance Co.*, [1924] S.C.R. 35, [1924] 1 D.L.R. 127 [*Ontario Metal Products Co. (S.C.C.)* cited to D.L.R.].

<sup>23</sup> *Ontario Metal Products Co.*, *ibid.* at 588.

<sup>24</sup> *Ibid.*

mean every factor could be considered material. There must be some *relation* between the fact and the risk. It would clearly be unreasonable for insurers to require declarations about circumstances that have no relation to the risk.<sup>25</sup>

Insurers have to demonstrate that particular information is *relevant* to the risk being insured. A simple affirmation by insurers that specific diseases constitute material circumstances that prohibit them from offering insurance is not enough,<sup>26</sup> “even if this affirmation is corroborated by other insurers.”<sup>27</sup> Unfounded fears and unscientific assumptions cannot be invoked to argue that some fact would have influenced an insurer in concluding a contract. If an insurer refuses to pay out on the basis of an alleged breach of disclosure of material information, courts will require that the insurer prove, through the use of actuarial tables, that there is a reasonable basis for qualifying a fact as “material to the risk.” This could be important in the context of genetics. As long as there is no scientifically strong evidence to support the link between a gene and a disease, insurers should have a hard time proving the materiality of a test.

While the insurance law of the common law approaches the issue of duty of disclosure fundamentally from the perspective of the reasonable insurer, this is not at all a crucial element for a well functioning insurance system. Under Quebec law, the duty of full representation is properly met if people declare everything “a normally provident insured” would declare, as long as there is no material concealment.<sup>28</sup> This is slightly different from the perspective of a “reasonable insurer.” The Quebec provision is not unique. As I will mention further, in other jurisdictions, including Australia and Belgium, the duty of disclosure is also fulfilled if an insurance applicant has made every disclosure a reasonable insured would consider to be material to the risk.<sup>29</sup>

Another important aspect of the duty to disclose that can give rise to discussions in the context of genetics is the fact that insurance applicants only have to declare what they know. The idea behind this is that there has to be a full exchange of information to avoid information asymmetry and abuse of information by applicants. The *Uniform Insurance Act* limits the duty of disclosure to facts within the knowledge of the insurance applicant.<sup>30</sup> As Norwood and Weir point out:

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<sup>25</sup> Jean-Guy Bergeron, “La déclaration du risque et les assurances-vie de non-fumeur” (1988) 48 R. du B. 47 at 50-51.

<sup>26</sup> Brown & Menezes report how in the early days of insurance, a practice developed of requesting warranties about the accuracy of all statements that were the basis of the insurance contract. These warranties were then used to deny coverage when a minor inaccuracy was found. This is why the law now explicitly states the duty of disclosure only applies to facts that are material to the risk. See *supra* note 17 at 5-3.

<sup>27</sup> *Beaulieu v. Industrielle, cie d'assurance sur la vie*, *supra* note 21 at 224-25.

<sup>28</sup> Art. 2409 C.C.Q.

<sup>29</sup> Tony McGleenan, “Insurance, Genetics and the Law” in McGleenan, Wiesing & Ewald, *supra* note 14, 75 at 77-78.

<sup>30</sup> *O.I.A.*, *supra* note 16, s. 183.

[i]f the insured or life insured does not actually know of the matter in dispute, they cannot be guilty of a misrepresentation ... notwithstanding that the unknown fact is a material fact which would have caused the insurer to decline the risk.<sup>31</sup>

However, inadvertent non-disclosure, for example when applicants have forgotten a material element they clearly should have been aware of, still remains an unlawful dereliction of their duty.<sup>32</sup>

A distinction can also be made between facts and personal opinions or beliefs.<sup>33</sup> Applicants do not have to disclose, for example, their own *impressions* about their life style or health habits, since there is so much subjectivity in this type of assessment. Applicants also do not have to interpret their own state of health, or engage in personal diagnoses of their symptoms.

When it comes to genetics, applicants can only be held responsible for failure to disclose material facts if they are themselves aware of their genetic constitution. Insurers would be unable to allege misrepresentation even if the genetic information were material to the risk covered. There is no obligation on the part of insurance applicants to go to great lengths to determine all potential risk factors. In practice, the application of this principle might discourage people from undergoing genetic tests or seeking genetic counselling, since as long as they can claim ignorance they will have no duty to report. People who have been advised to undergo genetic testing would, however, have a duty to disclose this fact to the insurer, if their status as candidates for genetic testing *per se* indicates they are at higher risk. Similarly, one could argue that if they know that a blood-relative has undergone genetic counselling and realize this means they are also at increased genetic risk, they would have to divulge that to insurers as well. Such a duty could even more easily be found if a genetic counsellor has explicitly told that family member to advise the insurance applicant to go for genetic counselling. It must be reiterated, however, that this will only be the case if the genetic risk factor is considered material. Genetic information is often unclear and easily misunderstood by non-specialists, including family physicians.<sup>34</sup>

In practice, insurers will avoid having to rely on a spontaneous declaration of potential risk factors in the underwriting process by asking detailed questions of insurance applicants, which then have to be answered in utmost good faith, or by submission to medical examinations.

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<sup>31</sup> *Supra* note 13 at 301.

<sup>32</sup> See Brown & Menezes, *supra* note 17 at 5-2, n. 4. Norwood and Weir distinguish this from the case where an applicant told the insurer in response to a specific question that he could not "recall," suggesting that when applicants declare their doubt, they have fulfilled their duty (See Norwood & Weir, *supra* note 13 at 306, n. 53).

<sup>33</sup> Norwood & Weir, *supra* note 13 at 299.

<sup>34</sup> See D.C. Wertz & J.C. Fletcher, "Privacy and Disclosure in Medical Genetics Examined in an Ethic of Care" (1991) 5:3 *Bioethics* 213.

Insurance companies use statistics on mortality and morbidity in trying to determine which applicants would make appropriate clients and at what cost coverage could be provided for them.<sup>35</sup> Underwriting usually leads to classification in one of three groups: standard, substandard, or uninsurable. People in the first group have few problems getting life or health insurance. People in the third group are excluded because the cost of their coverage would exceed any reasonable premium. People in the second group must pay higher than average premiums based on the risk they represent. Some pre-existing conditions are often excluded from coverage or are not covered for the first years of the contract.

Insurance companies classify the risk by asking questions, through medical investigations and often also by consulting a corporate data base on insurance applicants, known as the Medical Information Bureau (MIB). The MIB is a non-profit organization set up by the insurance industry to which most North American insurance companies send coded information about applicants and their risk status. When applicants sign an insurance contract, they most often give explicit permission to have basic information about their application sent to this data base. When an applicant signs a new contract, insurance companies verify whether there is any information on the applicant, for example, whether the applicant has ever been rejected.

The questions asked by insurance companies sometimes cover the medical histories of family members.<sup>36</sup> Depending on the case and the amount of coverage involved, medical questions (about habits, family diseases, professional activities, hobbies, and the like) might be followed by medical tests or complete medical examinations. For risk classification, the following factors have traditionally been used: age, sex, health history, physical condition, occupation, alcohol and tobacco consumption, family history, and serum cholesterol.<sup>37</sup> For men, many underwriting procedures now also include a test to determine their risk of developing prostate cancer. Insurers argue they need this information to assess risks for illness and death, to make decisions on the issuing of policies, and (if policies are issued) to determine the premiums and conditions of contracts.<sup>38</sup>

Genetic information, in the sense of information of family histories of disease, is already used by insurance companies to determine people's premiums. Some people with serious genetic conditions in the family may obtain a life insurance contract that excludes death related to the disease. People with a family history of Huntington's disease, for example, may be able to obtain life insurance

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<sup>35</sup> Ontario Law Reform Commission, *Report on Genetic Testing* (Toronto: Queen's Printer, 1996) at 112.

<sup>36</sup> *Ibid.*

<sup>37</sup> *Ibid.* at 92; Ontario, Legislative Assembly, Select Committee on Company Law, *The Insurance Industry: Fourth Report on Life Insurance* (Toronto: Queen's Printer, 1980) at 221.

<sup>38</sup> Henriette D.C. Roscam-Abbing, "Predictive Genetic Knowledge, Insurance and the Legal Position of the Individual" in Swiss Institute of Comparative Law, ed., *Human Genetic Analysis and the Protection of Personality and Privacy (International Colloquium)* (Zürich: Schulthess Polygraphischer Verlag, 1994) 143 at 146.

that would cover any unexpected death unrelated to the disease. The advent of genetic testing will, however, likely make it possible to determine with greater accuracy the risk status of individuals and thus increase concerns about potential exclusion of people with genetic susceptibilities from insurance coverage.

Several situations can be distinguished with respect to the use of genetic test results. Insurers could get genetic information through access to medical files, which is already the case at present. They could ask applicants specifically whether they have had genetic tests and what the results were (knowing that applicants have an obligation of utmost good faith). As I mentioned earlier, insurers have begun to argue that even if they do not ask specifically whether insurance applicants have undergone genetic testing, these applicants should divulge the results of such tests. The ground for this argument is the “*uberrima fides*” nature of insurance contracts and the concomitant disclosure obligation. Since applicants have to disclose everything a “reasonable insurer” would want to know, the insurers’ expressions of desire for this information may help them make the case that an insurance applicant should have known this is the type of information any reasonable insurer wants to know. Since a life insurance contract involves an agreement about a premium to cover against unknown risks in the future but based on knowledge of risk factors at the time of conclusion of the contract, insurance applicants do not have to reveal the results of genetic tests undergone after the conclusion of the contract. However, as Otlowski points out, “there may be an obligation to disclose testing has been undertaken [sic], even though the results may not yet be available.”<sup>39</sup>

Insurers could also get genetic information from family members and use this to classify families as high risk. Insurers could actually require testing. There is nothing that currently prohibits insurers from asking a person to undergo a genetic test for insurance purposes. Finally, they could offer lower premiums to those who submit test results indicating lower-than-average risk.

A serious sanction is attached to applicants’ untruthfulness in answering underwriting questions and to failures to respect the obligation to disclose. According to the *Uniform Insurance Act*, failures to disclose a material fact or misrepresentation render a life insurance contract voidable.<sup>40</sup> This means insurance companies have an option to invoke the misrepresentation to annul the contract. The misrepresentation of material facts could be grounds to annul contracts even when the facts are unconnected to the circumstances of the insured person’s death.<sup>41</sup>

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<sup>39</sup>Margaret F. Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice* (Occasional Paper No.1) (Tasmania: Centre for Law and Genetics, 2001) at 14 [*Implications of Genetic Testing*].

<sup>40</sup>*A.I.A.*, *supra* note 16, s. 567(2); *B.C.I.A.*, *supra* note 16, s. 41(2); *M.I.A.*, *supra* note 16, ss. 160(2), 219(2); *N.B.I.A.*, *supra* note 16, ss. 144(2), 202(2); *N.F.L.I.A.*, *supra* note 16, s. 14(2), 20(2); *N.S.I.A.*, *supra* note 16, ss. 185(2) and 82(2); *O.I.A.*, *supra* note 16, ss. 183(2), 308(2); *P.E.I.I.A.*, *supra* note 16, ss. 131(2), 191(2); *S.I.A.*, *supra* note 16, ss. 145(2), 242(2); *N.W.I.A.*, *supra* note 16, ss. 81(2), 185(2); *Y.I.A.*, *supra* note 16, ss. 85(2), 188(2). See also Art. 2410 C.C.Q.

<sup>41</sup>Norwood & Weir, *supra* note 13 at 298.

The reason is that misrepresentation undermines the very foundation of the formation of the insurance contract: insurers who would have been informed correctly about the circumstances relevant to risk could have refused to issue coverage, or would have offered coverage only at higher premiums.<sup>42</sup>

Both the *Uniform Insurance Act* and the *Quebec Civil Code* soften the duty of full disclosure by ruling that when a contract for life insurance or accident and sickness insurance has been in effect for two years, an inadvertent failure to disclose or a misrepresentation of a material fact does not, in the absence of fraud, render the contract voidable. If the misrepresentation is fraudulent, the law imposes no time limit; the contract can be voided at any time at the request of the insurer. Once two years have passed since the conclusion of an insurance contract, good faith on the part of the insured renders the policy non-contestable. The two-year period is a legal maximum imposed on insurers. They can provide by contract a shorter incontestability period but cannot stipulate a longer period.<sup>43</sup>

The short discussion of insurance law and how it applies in the context of genetics can be summarized here as follows: people who are informed of the result of a scientifically validated genetic test that indicates they are at a statistically significant higher risk of premature death or disability would have an obligation to disclose this to the insurance company. People also have to declare any other form of genetic information, such as family history of disease, which a reasonable insurer would want to know to determine premiums. The insurance company could charge a higher premium on the basis of that information. Disputes could arise as to what constitutes material information and to what extent such genetic information was known to the insurance applicants *at the time of their application*.

It is also important to point out that contractual freedom allows insurance companies to impose particular tests as a precondition for offering insurance coverage. Nothing in insurance law prohibits insurance companies from introducing specific genetic tests in the underwriting process. There is also no prohibition in current insurance law to make coverage for members of high risk families dependent on the submission of a negative genetic test result showing, for example, that they will not develop Huntington's disease. Genetic information, including the results of genetic tests, can thus be used in different ways: it can be the basis for a higher premium; it can lead to a refusal of coverage; and it can be used to lower an insurance premium or to accept coverage for a member of a high risk family.

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<sup>42</sup>Didier Lluelles, *Précis des assurances terrestres*, 3rd ed. (Montréal: Thémis, 1999) at 235.

<sup>43</sup>Norwood & Weir, *supra* note 13 at 105; see also Art. 2414, C.C.Q.

## 2. Human Rights Law

As has been discussed elsewhere in more detail,<sup>44</sup> Canadian human rights law does also offer some form of protection in the context of insurance. The *Canadian Charter of Rights and Freedoms*,<sup>45</sup> the *Canadian Human Rights Act*<sup>46</sup> and the human rights legislation of all Canadian provinces and territories prohibit discrimination and discriminatory practices on specific enumerated grounds, such as ancestry, race, marital status, sex, sexual orientation, disability and age. Discrimination provisions of provincial human rights statutes apply in the context of private life insurance contracts.

Two issues are to be addressed to determine whether someone with a genetic predisposition or susceptibility would be protected by anti-discrimination provisions. First, a genetic trait has to be identified with a specific enumerated or analogous ground. Following the recent case in *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City); Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand*,<sup>47</sup> there is little doubt the courts could qualify discrimination based on a genetic susceptibility or predisposition as discrimination based on handicap or disability.<sup>48</sup> In *Boisbriand*, the Supreme Court dealt with three complaints from people who had been excluded from employment as a result of medical examinations revealing asymptomatic conditions. Two individuals had spinal anomalies, while another had asymptomatic Crohn's disease. In all of these cases, there was no concrete physical ailment that impeded the plaintiffs from fulfilling their employment-related duties. The Court had to decide whether these asymptomatic conditions counted as a handicap, one of the enumerated grounds under the Quebec *Charter of Human Rights and Freedoms*.<sup>49</sup> The conditions dealt with in this case show a great resemblance to genetic susceptibilities or predispositions: they were asymptomatic conditions that did not reveal any concrete immediate problem, but created concern in the employer of predisposition to increased risk of injury or disease.

The second issue is that while these human rights statutes contain general prohibitions against discrimination, they also allow exceptions. The Ontario *Human Rights Code*,<sup>50</sup> for example, creates an explicit insurance exception to the

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<sup>44</sup> See Lemmens, "Selective Justice", *supra* note 5; H el ene Guay, Bartha Maria Knoppers & Isabelle Panisset, "La g en etique dans les domaines de l'assurance et de l'emploi" (1992) 52 R. du B. 185. These documents do not discuss more recent decisions of the Supreme Court which have, in my opinion, changed considerably the debate. A detailed analysis of human rights law in the context of genetics and insurance, based on a detailed analysis of recent caselaw can be found in Lemmens, *Genetic Information and Insurance*, *supra* note 11 at c. 7. An article discussing these developments is also forthcoming.

<sup>45</sup> Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11 [*Charter*].

<sup>46</sup> R.S.C. 1985, c. H-6.

<sup>47</sup> [2000] 1 S.C.R. 665 [*Boisbriand*].

<sup>48</sup> For a more detailed discussion, see Lemmens, *Genetic Information and Insurance*, *supra* note 11.

<sup>49</sup> R.S.Q. c. C-12.

<sup>50</sup> R.S.O. 1990, c. H-19 [*Ontario Human Rights Code*].

extent that distinctions in underwriting practices related to health are “reasonable and *bona fide*.”<sup>51</sup> Some other provincial human rights statutes state more generally that *bona fide* and reasonable distinctions can be reconciled with the anti-discrimination provision.

Until recently, the 1992 Canadian Supreme Court decision, *Zurich Insurance Co. v. Ontario (Human Rights Commission)*,<sup>52</sup> offered much leeway for insurers in determining whether a standard was a *bona fide* justification (BFJ) in the context of insurance. In *Zurich*, a majority of the Court ruled an insurance company could reasonably discriminate if the distinction made was based on “sound and accepted” insurance practice and if there was “no practical alternative.”<sup>53</sup> The Supreme Court thereby basically left it up to insurance companies to determine whether a discriminatory distinction could be defended as a “sound and accepted” insurance practice. If a distinction was part of industry practice, it could be seen as acceptable. The test could easily be connected to the duty under insurance law to disclose everything a reasonable insurer would want to know and left much of the discretion about insurance underwriting in the hands of the insurers.

It can be argued that *Zurich* has been superseded by the recent decisions in *Meiorin* and *Grismer*.<sup>54</sup> The *Meiorin* and *Grismer* decisions have introduced a new uniform test to determine whether a standard can be justified as a *BFJ*. A detailed discussion of the shift in Canadian equality law created by these cases and its impact on insurance law exceeds the scope of this paper, but it can be pointed out that in these and other subsequent cases, the Supreme Court emphasized there is only one general test to determine whether a discriminatory practice qualifies as a *BFJ*. The Court also imposed a high evidentiary standard for the justification of a discriminatory practice. The Supreme Court’s emphasis on the need to support a discriminatory practice with clear and substantial evidence is much more demanding than the weak “sound and accepted insurance practice” test adopted in *Zurich*. Of equal importance is the Supreme Court’s emphasis in these cases on the duty of accommodation as an obligation on the insurer to look for reasonable alternatives to a discriminatory practice. The Court called upon

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<sup>51</sup> *Ibid.*, s. 22.

<sup>52</sup> [1992] 2 S.C.R. 321 [*Zurich*]. This case concerned a complaint made by a 25 year-old male that his insurance provider had discriminated against him on the basis of age, sex and marital status in the provision of a service, namely automobile insurance. For further discussion of the case, see: Lemmens, “Selective Justice”, *supra* note 5 at 405-406; Trudo Lemmens & Poupak Bahamin, “Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis” in Bartha Maria Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville, Qc.: Yvon Blais, 1998) 107 at 198-201.

<sup>53</sup> *Zurich, ibid.* at 342. It is interesting to point out that the two very strongly worded dissenting opinions in this case came from L’Heureux-Dubé and McLachlin JJ. (as the latter then was). Both have written the reasons in some of the determinant human rights cases that are discussed here and that have, as discussed, expanded the potential use of human rights statutes in the context of genetics.

<sup>54</sup> *B.C. (Superintendent of Motor Vehicles v. B.C. (Human Rights Commission)*, [1999] 3 S.C.R. 868; *British Columbia (Public Service Employee Relations Commission) v. B.C.G.S.E.U.*, [1999] 3 S.C.R. 3 [*Meiorin*]

the parties to be inventive in trying to find ways to avoid the impact of discriminatory practice. The discussion hereafter of various policy options is undertaken in the spirit of this call for alternative approaches. It is important to investigate whether Canadian insurance policy and practice could be changed, in line with developments in other countries, and in a way that offers better protection and fuller integration in social life of those who are at risk of being discriminated against on the basis of their genetic traits.

### 3. Limits of Current Protection in Canada

From the previous discussion, it should be clear that there are some legal restrictions in Canada on the use of genetic information by insurance companies. If an insurer refuses to pay out and alleges the insurance applicant breached his or her duty to disclose the presence of a genetic risk factor at the time of concluding the contract, courts will assess whether that genetic information was 'material' and whether the applicant knew about the existence of this risk factor. If applicants challenge that decision in court, the court will determine whether the genetic information is of the kind a reasonable insurer would want to know in order to determine an insurance premium. Evidence will thus be required to determine whether there is any statistical support for arguing a genetic factor predisposes someone to increased risk of premature death or disability.

There is also protection under human rights law. People who are excluded on the basis of a genetic trait could invoke anti-discrimination provisions of the provincial human rights statutes. Courts or human rights tribunals will then have to analyze whether the challenged underwriting practice, in this case the use of a genetic test result, or the imposition of a test as precondition for coverage, constitutes a BFJ. This will also require an assessment of the actuarial basis for the underwriting practice. As a result of the recent Supreme Court cases, this would involve more than a simple reliance on existing insurance underwriting practices and on actuarial data developed by industry. A BFJ analysis, even in the context of insurance, now requires an in depth analysis of the strength of the scientific evidence and even an assessment of potential alternatives.

The existing legal protection remains limited, however. Although courts may reject insurers' claims that applicants should have disclosed specific genetic information when the link between a genetic mutation and a risk factor is insufficient or not well established, many forms of genetic information can still be used and genetic tests can still be imposed as a precondition for insurance coverage. Moreover, the evaluation of the 'materiality' of genetic information by the courts happens when there is a dispute. Parties have to go to court, and it is easy to see how insurance companies are in a better position to engage in lengthy court proceedings than are individual insurance applicants.

The same problem exists with the anti-discrimination mechanisms. They are generally reactive rather than pro-active. In order to obtain protection under the *Ontario Human Rights Code*, for example, an individual must file a complaint stating he or she has been the object of discrimination based on one of the specified

grounds.<sup>55</sup> The ensuing process is also lengthy and costly for all parties involved.<sup>56</sup> Moreover, it does not contribute to the development of clear and transparent policies, which are of interest to both consumers and members of the insurance industry.

#### 4. Concerns About the Use of Genetic Information

Why is a better protective regime required? What are the concerns? Various arguments have been invoked to justify restrictions on insurers' right to obtain access to genetic information or to conduct genetic testing. A fundamental argument is related to the more general concern that the advent of genetic testing may significantly affect those with a genetic predisposition or a genetic susceptibility in all walks of life. It is feared that those people will be affected in many different social activities and become excluded from employment and insurance, have problems with immigration and may generally be stigmatized and isolated. This could lead to what has been called a "genetic proletariat," and it could also augment discrimination of already marginalized groups.<sup>57</sup>

But there are more specific reasons to be concerned about the unbridled use of genetic testing for insurance purposes. It has been argued that giving insurers access to genetic information contained in medical files could discourage people from being tested.<sup>58</sup> Getting and using information from the results of genetic tests on family members would infringe on their privacy and violate the "right not to be informed."<sup>59</sup> Those denied coverage could be informed they are at risk for disabling diseases without ever having been aware of the fact that these run in their family. Offers of lower insurance premiums might pressure those with family histories of incurable illness to be tested. Ostrer argues that "individuals who, on the basis of family history of a dominant disease, such as Huntington's disease, have been denied insurance, may *seek* testing, because a negative test result would render them

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<sup>55</sup> *Supra* note 50, s. 32(1). The Human Rights Commission may also initiate a complaint by itself, or at the request of any person: s. 32(2).

<sup>56</sup> See Part IV of the *Human Rights Code*, *ibid.*, for enforcement procedures.

<sup>57</sup> See the discussion in Lemmens, *Genetic Information and Insurance*, *supra* note 11

<sup>58</sup> See H. Ostrer, *et al.*, "Insurance and Genetic Testing: Where Are We Now?" (1993) 52 *Am. J. Hum. Gen.* 565 at 570: "Individuals who might benefit from presymptomatic detection and treatment of disease [...] may avoid testing, for fear that a positive result might lead either to an increase in insurance rates or to complete or partial denial of coverage for their genetic diseases." See also L.O. Gostin, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers" (1991) 17 *Am. J. Hum. Gen.* 109 at 113; Trudo Lemmens, "L'utilisation de l'information génétique par les compagnies d'assurance" *Actualité médicale* (29 September 1993) 42 at 43; Jennifer Miller, "Physician-Patient Confidentiality and Familial Access to Genetic Information" (1994) 2 *Health L.J.* 141 at 151; Laura Rowinski, "Genetic Testing in the Workplace" (1988) 4 *J. Contemp. Health L. & Pol'y* 375 at 409.

<sup>59</sup> See Roscam-Abbing, *supra* note 38 at 144; Sonia M. Suter, "Whose Genes are these Anyway? Familial Conflicts over Access to Genetic Information" (1993) 91 *Mich. L. Rev.* 1854 at 1893; Bernard M. Dickens, Nancy Pei & Kathryn M. Taylor, "Legal and Ethical Issues in Genetic Testing and Counselling for Susceptibility to Breast, Ovarian and Colon Cancer" (1996) 154 *Can. Med. A. J.* 813 at 814; Privacy Commissioner of Canada, *Genetic Testing and Privacy* (Ottawa: Supply and Services, 1995) at 30.

insurable.”<sup>60</sup> Some Canadian insurers have indeed told applicants with family histories of Huntington’s disease they would have to be tested before getting insurance.<sup>61</sup> Nevertheless, those who previously would have been denied insurance or had to pay very high premiums can now benefit from genetic testing by proving they are not at risk.<sup>62</sup> Those who test positive, of course, would either be denied every form of coverage, see their premiums increase, or receive coverage with exclusion criteria linked to their genetic susceptibilities.

It has been pointed out that the need for insurance is not a “clinically appropriate” reason to undergo testing. Genetic testing for such a serious condition should not take place as a result of economic pressure, in this case a need to obtain life insurance. This situation might not offer the appropriate circumstances for genetic testing and counselling. Allowing insurers to require testing, it could be argued, removes genetics from the medical context. It gives insurers a lot of power, albeit indirect, over the intimate medical decision whether or not to undergo genetic testing. Systematic use of tests outside the medical context may also increase the pressure for genetic conformity. What happens when genetic traits become more than a burden to personal health? Should carriers of hereditary cancers be pressured not to have any more children? People with family histories of genetic diseases or who are carriers of genetic disorders often find it difficult to buy coverage to benefit their dependants.<sup>63</sup> This form of insurance is normally issued with little or no evidence of insurability.<sup>64</sup> It will have to be debated whether insurance companies really need this information. A compromise may have to be found, one that would protect personal decision making, medical privacy, reproductive freedom, and societal benefits – as well as the financial interests of the insurance industry.<sup>65</sup>

## **B. A Comparative Perspective of Other Legal and Policy Options**

But are there other options? In the remainder of this paper, I give an overview of different approaches employed internationally to deal with the issue of genetics and life insurance. My comments about these different policies will necessarily be of a general nature since I cannot discuss here at any length the entire legal, economic and policy contexts in which these policies operate. The aim of this discussion is neither to provide a very detailed assessment of the appropriateness of these policies for the specific countries in which they have been adopted, nor to give a comprehensive overview of the international developments. The latter would require a more detailed comparative inquiry, which has been undertaken elsewhere

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<sup>60</sup> Ostrer *et al.*, *supra* note 58 at 570.

<sup>61</sup> See Lemmens & Bahamin *supra* note 52.

<sup>62</sup> Marne E. Brom, “Insurers and Genetics: Shopping for that Perfect Pair of Genes” (1991) *Drake L. Rev.* 121 at 136.

<sup>63</sup> Representatives for the Huntington’s Society indicated to me that several of their members reported they were refused any form of life insurance because of a family history of Huntington’s disease.

<sup>64</sup> Pointed out by Luc Plamondon, (Personal communication).

<sup>65</sup> Roscam-Abbing, *supra* note 38 at 150.

by myself and others.<sup>66</sup> References to developments in other countries will provide a background from which to discuss the viability or appropriateness of these options in consideration of the Canadian context.

Commentators have created different categories when analyzing the various approaches towards the regulation of the use of genetics in insurance. Among the problems with using these categories, or for comparing the proposed solutions as discussed by these commentators, is that many discuss issues related to both health and life insurance, while others focus exclusively on legal options dealing with life insurance, and still others refer to more general approaches towards genetic discrimination, which include genetic discrimination in other contexts, such as employment. I will focus on those commentators who have addressed more specifically genetic discrimination in insurance.

Tony McGleenan and Urban Wiesing, in a text analyzing policy options for health and life insurance, distinguish “macro solutions,” “mid level solutions” and “micro solutions.”<sup>67</sup> Their allocation and analysis of various options under these very general headings is sometimes confusing. For example, under macro solutions, they situate the option of altering the entire insurance market with an absolute prohibition of the use of genetic information. Among mid level solutions, they refer to soft regulation of the insurance market, industry self-regulation, moratoria and ceiling systems, altering the disclosure laws, and include a separate category called “national legislation.” The latter category does not seem to fit with the others, since national legislation is clearly a means by which to achieve some of the solutions they had put in other categories, including absolute prohibitions (a macro-level solution) and altering the disclosure laws (discussed among both mid-level and micro solutions). Micro solutions, in their view, are those that deal with the development of specific insurance products or of short-term solutions to specific concerns. In the latter category, they discuss, for example, how people could be encouraged or required to obtain insurance prior to undergoing genetic testing.

Bartha Maria Knoppers, Béatrice Godard and Yann Joly, in a chapter focussing exclusively on life insurance and genetics, discuss as separate categories a human rights approach, a “therapeutic” approach, a prohibitive approach, a moratorium approach and the status quo.<sup>68</sup> Their human rights and therapeutic

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<sup>66</sup> For a more comprehensive overview of international developments related to insurance, see EURO-GAPPP Project, European Society of Human Genetics, Public and Professional Policy Committee, *Genetic Information and Testing in Insurance and Employment: Technical, Social and Ethical Issues*, by Béatrice Godard *et al.* (30 January 2002), online: European Society of Human Genetics <<http://www.eshg.org/ESHG%20insurance%20bckgrnd.pdf>> [*Genetic Information and Testing*]; Bartha Maria Knoppers, Béatrice Godard & Yann Joly, “Life Insurance and Genetics: A Comparative, International Overview” in Mark A. Rothstein, *Life Insurance: Medical Underwriting and Social Policy* (Boston: MIT Press, forthcoming); Jürgen Simon, *Gendiagnostik und Versicherung: Die Internationale Lage im Vergleich* (Lüneberg: Universität Lüneberg, 2000) [*Gendiagnostik und Versicherung*]; and Lemmens & Bahamin, *supra* note 52, in particular at 239-270.

<sup>67</sup> Tony McGleenan & Urban Wiesing, “Policy Options for Health and Life Insurance in the Era of Genetic Testing” in McGleenan, Wiesing & Ewald, *supra* note 14, 115.

approaches overlap somewhat, since they discuss in the latter the approach followed by the *European Convention on Human Rights and Biomedicine*, which expresses the idea that genetic testing should only be undertaken for health care purposes. I will discuss this *Convention* in more detail later in the chapter.

Margaret Otlowski, in a discussion paper focusing on life insurance but referring to the larger insurance context, analyses three different options: retention of the status quo (*i.e.* potential use of statistically relevant genetic information), blanket prohibition and the introduction of a ceiling or threshold.<sup>69</sup> Jürgen Simon, in a comparative study, reports on various policy options for both health and life insurance contracts, but discusses these options separately for each type of insurance.<sup>70</sup> He also distinguishes three categories: (1) no limits on the use of genetic testing in insurance; (2) limited use of genetics; and (3) prohibition of the use of genetics.

For the purpose of this article, I will discuss various options in the following order, with particular attention to areas of law that have been introduced previously: (1) introducing a moratorium on the use of genetic testing and its results in insurance; (2) promoting self-regulation by the insurance industry; (3) making changes within existing insurance statutes; and (4) adapting existing human rights law. Within the third category, I will discuss three major different approaches and some specific smaller options for change. The three major approaches include: an absolute prohibition; a ceiling system; and guaranteeing access to insurance while putting a cap on the pay-out of coverage related to a known genetic risk. The discussion of potential changes to human rights law in the fourth part cannot be entirely separated from the third part, where I discuss, for example, the introduction of prohibitions. Indeed, prohibitions on the use of genetics can also be introduced by human rights law. Where appropriate, I will discuss these in conjunction.

## 1. Moratorium on Genetic Testing for Insurance Purposes

In several countries, moratoria have been introduced by the insurance industry in response to concerns expressed by commentators and consumer groups. Sometimes, the enactment of these moratoria is clearly related to official reports or specific pressure from governmental organizations. In other cases, insurance organizations have made official declarations without an identifiable source of pressure. But clearly, these enactments are the political response of the industry to the kinds of concerns discussed previously. The enactment of a moratorium cannot be discussed as a uniform solution to any of the concerns related to issues of adverse selection or fairness, since moratoria have been enacted or more informally suggested in different forms. Some of them are all-encompassing in that they involve an absolute ban on the use of any genetic test results for insurance purposes. Others

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<sup>68</sup> *Supra* note 66.

<sup>69</sup> *Implications of Genetic Testing*, *supra* note 39 at 46-68.

<sup>70</sup> *Supra* note 67 at 88-150.

are more limited and imply a commitment by the industry not to introduce genetic tests as a pre-condition for an insurance contract but without restriction on the use of genetic test results that are known to applicants. When the commitment of the industry has been made through a limited public statement, such as in Canada,<sup>71</sup> the precise content of the moratorium may remain unclear. I will not discuss in detail the advantages of the terms of these moratoria: advantages of absolute versus limited bans on the use of genetics will be discussed under the proposed legislative options.

According to Knoppers, Godard and Joly, some form of moratorium has been supported by the insurance associations or actuarial organizations of Australia, Canada, Finland, France, Germany, Greece, Ireland, New Zealand, South Africa, Sweden, Turkey and the United Kingdom.<sup>72</sup> In many of these countries, the moratoria have a limited significance, since they basically confirm the established practice, *i.e.*, that insurers do not request genetic tests as a pre-condition for any insurance contract, although they maintain their right to ask questions about test results known to applicants.<sup>73</sup> This prevalent form of moratorium confirms that the actuarial value of genetic testing is currently too limited to make them useful for insurance purposes. As discussed earlier, genetic tests are still expensive and they are of limited value for underwriting purposes as predictive tests, except for some relatively rare monogenic diseases, for which familial risk information is most often already available and used by the industry. Although some of these moratoria may impose some limits on the actuarial use of genetic data,<sup>74</sup> this form of moratorium does not constitute a very significant commitment by the industry but serves mainly as a reassurance that there is no imminent change to existing insurance company policies.<sup>75</sup> It is also obviously not a long term solution since the value of these genetic tests to industry may increase as they become cheaper and as their predictive

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<sup>71</sup> See text accompanying notes 2-4 for the exchange of letters between the President of the Canadian Cancer Society and the President of the Canadian Life and Health Insurance Association Inc.

<sup>72</sup> *Supra* note 66 at 16.

<sup>73</sup> Knoppers, Godard and Joly mention Australia, Canada, Greece, New Zealand and South Africa. For Australia, see the more detailed discussion in Otlowski, *Implications of Genetic Testing*, *supra* note 39 at 24-26. See also Margaret Otlowski, "Resolving the Conundrum: Should Insurers Be Entitled to Access to Genetic Test Information?" (2000) 11 *Ins. L. J.* 193 at 201-202 ["Resolving the Conundrum"].

<sup>74</sup> Otlowski discusses, for example, in some detail the position of Australia's life insurance and superannuation organization, the Investment and Financial Services Association Ltd. The organization states in a position paper of 1996 (*Position Paper on Genetic Testing and Life Insurance*, 1996), updated in 1999 (*Underwriting and Genetic Testing: Draft Policy on Genetic Testing*, 1999), that it will not initiate genetic testing on applicants for insurance and, to avoid indirect pressure to undergo testing, will not use genetic test results as a basis to offer lower than standard rate premiums. It does, however, insist on the right of insurers to request to be informed of existing results. It also contains recommendations with respect to confidentiality of genetic information and the requirement of informed consent. The policy was approved by the Australian Competition and Consumer Commission in November of 2000 for a period of two years. See: *Implications of Genetic Testing*, *ibid.* at 24-26; and Otlowski, "Resolving the Conundrum", *ibid.* at 201.

<sup>75</sup> This point is also made by Tony McGleenan & Urban Wiesing, "Insurance and Genetics: European Policy Approaches" (2000) 7 *Eur. J. Health L.* 374, cited in Knoppers, Godard & Joly, *supra* note 66 at 16.

value increases. To the extent these moratoria do confirm the right of insurers to ask for existing test results, they do not offer any reassurance for those people who want to undergo genetic testing for clinical purposes or want to participate in research and are worried about the insurance consequences.

More significant commitments were undertaken in countries where the moratoria cover all use of the results of genetic tests for insurance purposes. Insurers in Finland,<sup>76</sup> France,<sup>77</sup> Germany,<sup>78</sup> the Netherlands,<sup>79</sup> Ireland,<sup>80</sup> Sweden<sup>81</sup> and the United Kingdom<sup>82</sup> all committed themselves at one point to this extent. However, as Knoppers, Godard and Joly observe, there are also limitations to the commitments expressed through these moratoria. First of all, the moratoria contain a specific time limit, often five years, and are subject to reconsideration. Equally important is the fact that many of them only apply for insurance contracts that do not exceed a certain amount.<sup>83</sup> As Knoppers, Godard and Joly further note,<sup>84</sup> insurance companies thus show a willingness to offer access to some form of insurance coverage without discriminating on the basis of genetics, while avoiding the potentially more significant form of adverse selection that can result from individuals at high risk taking out high amounts of coverage.<sup>85</sup> Béatrice Godard and

<sup>76</sup> See *Genetic Information and Testing*, *supra* note 66; Knoppers, Godard & Joly, *ibid.*

<sup>77</sup> France, "Étude génétique des caractéristiques d'une personne: l'engagement des assureurs de la FFSA" (1994/1999), cited in Knoppers, Godard & Joly, *ibid.*; *Genetic Information and Testing*, *ibid.*

<sup>78</sup> German Insurance Association, *Voluntary Agreement on the Use of Genetic Testing for Insurance* (Berlin: German Insurance Association, 2001), cited in Knoppers; Godard & Joly, *ibid.*

<sup>79</sup> A first moratorium was enacted by the industry in 1990 and was extended for another five years in 1995. For a more detailed discussion, see Lemmens & Bahamin, *supra* note 52 at 255-56; Herman Nys *et al.*, *Predictive Genetic Information and Life Insurance; Legal Aspects: Towards European Policy?* (Maastricht: University of Limburg, 1993) at 9; Per Sandberg, "Genetic Information and Life Insurance: A Proposal for an Ethical European Policy" (1995) 40 *Social Sci. & Med.* 1549 at 1557. It has since then been replaced by a legislative initiative. See section C.2 below for a discussion of the new legislation.

<sup>80</sup> Irish Insurance Federation, *Code of Practice on Genetic Testing* (Dublin: Irish Insurance Federation, 2001), online: Irish Insurance Federation <<http://www.iif.ie/media.htm>>.

<sup>81</sup> Sweden, *Agreement Between Swedish State and the Swedish Insurance Federation concerning Genetic Testing* (May 1999), cited in Graeme T. Laurie, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press, 2002) at 149; *Genetic Information and Testing*, *supra* note 66 at 27; Knoppers, Godard & Joly, *supra* note 66. The moratorium is also mentioned in *Gendiagnostik und Versicherung*, *supra* note 66 at 146.

<sup>82</sup> A first moratorium was enacted by the Association of British Insurers in 1997. See Association of British Insurers, *Genetic Testing: ABI Code of Practice* (London: Association of British Insurers, 1997) [*Code of Practice*]. A second was announced in 2001 and resulted from an agreement with the government. See U.K., Department of Health, *Government Response to the Report from the House of Commons Science and Technology Committee: Genetics and Insurance* (London: Her Majesty's Stationery Office, 2001), online: U.K., Department of Health <<http://www.doh.gov.uk/genetics/gaicgovrespoct2001.pdf>>, cited in Knoppers, Godard & Joly, *supra* note 66.

<sup>83</sup> This is the case for Germany, *supra* note 79; Ireland, *supra* note 80; Sweden, *supra* note 81 and in the past also under the Dutch and the United Kingdom moratoria. The Dutch moratorium has been replaced by legislation, and the U.K. moratorium has become a more absolute one. Knoppers, Godard & Joly, *ibid.*

<sup>84</sup> *Ibid.* at 18.

<sup>85</sup> Interesting analyses of adverse selection have been undertaken by A. S. Macdonald and, in Canada, by Michael Hoy. See *e.g.*, A. S. Macdonald, "Genetics and Insurance: What Have We Learned So Far?" *Scandinavian Actuarial J.* [forthcoming 2003], online: Heriot-Watt University

colleagues, in a report for the European Society for Human Genetics, state the moratorium approach “affords the insurance industry time to formulate an alternative policy strategy.”<sup>86</sup> The use of a moratorium also provides flexibility, since it is not binding.<sup>87</sup> It can always be lifted when the circumstances change, although insurers are also aware this could provoke negative public reactions.

The example of the United Kingdom is worth mentioning here to indicate how public opinion and governmental initiatives often interact and how they can have a significant impact on proposed industry practices.<sup>88</sup> The first moratorium enacted in the United Kingdom was issued by the industry in reaction to a critical report of the House of Commons Select Committee on Science and Technology<sup>89</sup> and to specific recommendations in a special insurance report by the Human Genetics Advisory Commission.<sup>90</sup> In its 1995 report, the House Committee ordered the insurance industry to produce a satisfactory proposal on genetic testing within one year or else face legislative restrictions. The Human Genetics Advisory Commission was established, in December 1996 following the House Committee’s report, with the mandate to review scientific progress in human genetics, to report on social, ethical and economic issues of genetics, and to develop public information mechanisms.<sup>91</sup> The Commission’s insurance report recommended that insurers issue a moratorium on the disclosure of genetic testing and urged the government

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<<http://www.ma.hw.ac.uk/~angus/papers/genep.pdf>>; A.S. Macdonald, “Human Genetics and Insurance Issues” in Iain Torrance, ed., *Bio-ethics for the New Millennium* (Edinburgh: St. Andrew Press, 2000) 25; A.S. Macdonald, “How Will Improved Forecasts of Individual Lifetimes Affect Underwriting?” (1997) 3 Brit. Actuarial J. 1009; A.S. Macdonald, “Modeling the Impact of Genetics in Insurance” (1999) 3 North Am. Actuarial J. 83. See also M. Hoy, & P. Lambert, “Genetic Screening and Price Discrimination in Insurance Markets” (2000) 25 Geneva Papers on Risk and Insurance Theory 103; and M. Hoy, & M. Polborn, “The Value of Genetic Information in the Life Insurance Market” (2000) 78 J. Public Econ. 235.

<sup>86</sup> *Genetic Information and Testing*, *supra* note 66 at 10.

<sup>87</sup> *Ibid.* at 10-11, where they state that “since moratoria are voluntary, they may only survive for as long as there are no commercial advantages to be gained in using genetic information.”

<sup>88</sup> I am grateful to Kathleen Liddell, doctoral student at the University of Oxford, for sharing her information with me and for discussing the U.K. developments. For a good report on the developments in the United Kingdom until 2001 and for an overview of the different committees involved in this debate, see U.K., H.C., Science and Technology Committee, “Genetics and Insurance” 5th Report, HC Paper 174 (London: Her Majesty’s Stationery Office, 2001), online: U.K. Parliament

<<http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmselect/cmsctech/174/17402.htm>> [“Genetics and Insurance”]. For a succinct overview of the most recent developments on insurance and genetics in the United Kingdom, see Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (London: Human Genetics Commission, 2002) at 121-122. See also *Genetic Information and Testing*, *supra* note 66 at 29-33; and T. McGleenan, “Insurance, Genetics and the Law”, *supra* note 29 at 84.

<sup>89</sup> U.K., H.C., Science and Technology Committee, “Human Genetics: The Science and Its Consequences” 3d report, vol. 1 (London: Her Majesty’s Stationery Office, 1995) [“The Science and Its Consequences”].

<sup>90</sup> U.K., Human Genetics Advisory Commission, *The Implications of Genetic Testing for Insurance* (London: Department of Trade and Industry, 1997), cited in Science and Technology Committee, “Genetics and Insurance”, *supra* note 88 at para. 13.

<sup>91</sup> Science and Technology Committee, “Genetics and Insurance”, *ibid.*

to establish an evaluation structure for the use of genetics in insurance.<sup>92</sup> The industry's response came in 1997, after consultation with the government. It consisted of the development of a new *Code of Practice*, which contained detailed guidelines with respect to genetics and was declared binding for a two-year period.<sup>93</sup> While the industry's *Code of Practice* contains a limitation on the use of genetic testing for insurance, the terms of this limitation are more limited than the Human Genetics Advisory Commission had recommended. According to the *Code*, insurers may not ask people to undergo genetic tests when they apply for insurance. It further provides that insurers may not ask for the results of genetic tests in connection with life insurance contracts that are directly linked to a mortgage for a private house of up to \$100,000.<sup>94</sup> For other contracts, however, insurers are allowed to use genetic information available to insurance applicants to determine premiums. Along with the moratorium, the industry association also appointed a special advisor on genetics whose opinion would be sought, according to the *Code of Practice*, in the determination of the scientific validity and predictive power of new genetic tests. It is worth mentioning that the *Code of Practice* also contained a detailed procedural appeals mechanism for insurance applicants who want to contest a decision by an insurance company to refuse coverage or to charge an increased fee. The *Code* thus introduced a full fledged procedural self-regulatory scheme to deal with disagreement around underwriting practices. I will discuss the self-regulation approach later.

The government also responded to the recommendations of the Human Genetics Advisory Committee.<sup>95</sup> In its response, the government agreed a permanent ban on the use of genetic testing was not desirable, but it felt some regulation was needed. It recommended the establishment of a permanent independent mechanism for the evaluation of genetic tests. This resulted in the establishment in 1999 of a specialized commission, the Genetics and Insurance Committee,<sup>96</sup> mandated to develop criteria for the evaluation of genetic tests. This is a more independent and official alternative to the evaluation system proposed by the industry in its *Code of Practice*, a mechanism which – correctly, in my view – has been held to be affected by problems of partiality and conflict of interest.<sup>97</sup> In the year 2000, the Genetics and Insurance Committee published its criteria for the approval of tests and developed an approval form.<sup>98</sup>

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<sup>92</sup>U.K., Human Genetics Advisory Commission, *supra* note 90.

<sup>93</sup>*Code of Practice*, *supra* note 82.

<sup>94</sup>This provision is of particular importance because in the U.K., life insurance is a precondition to obtaining a mortgage for a house. Being excluded from life insurance thus also excludes people from access to ownership.

<sup>95</sup>U.K., Department of Trade and Industry, Office of Science and Technology, *Government Response to the Human Genetics Advisory Commission's Report on The Implications of Genetic Testing for Insurance* (London: Department of Trade and Industry, 1998).

<sup>96</sup>See Science and Technology Committee, "Genetics and Insurance", *supra* note 88 at paras. 15-16.

<sup>97</sup>McGleenan, "Insurance, Genetics and the Law", *supra* note 29 at 87.

<sup>98</sup>See Science and Technology Committee, "Genetics and Insurance" *supra* note 88 at para. 15. The three criteria it introduced are: technical relevance, clinical relevance and actuarial relevance.

The development of this evaluation structure was clearly intended to provide an independent form of review, that would reassure the public and steer private insurance towards the “public interest.”<sup>99</sup> However, its first approval stirred considerable controversy. The Genetics and Insurance Committee announced in the fall of 2000 that the results of the genetic test for Huntington’s disease were sufficiently reliable and relevant for actuarial purposes to warrant its use.<sup>100</sup> The composition of the Genetics and Insurance Committee was denounced – in particular, the fact that the representative on the committee of the Association of British Insurers had been directly involved in the evaluation of the Huntington’s test application, an application which he himself had prepared.<sup>101</sup> The controversy was exacerbated by the fact that, independent of governmental initiatives and the work of these committees, the Association of British Insurers had itself distributed among its members, following the advice of its own Genetics Advisor, a list of ten tests for seven genetic conditions (Huntington’s disease, early onset Alzheimer’s disease, hereditary breast and ovarian cancer, myotonic dystrophy, familial adenomatous polyposis, multiple endocrine neoplasia and hereditary motor and sensory neuropathy), which it recommended as sufficiently reliable to be used for insurance purposes.

The resulting uncertainty was heavily criticized in the 2001 House of Commons’ Science and Technology Committee report on “Genetics and Insurance” which followed extensive hearings and debate.<sup>102</sup> The recommendations and conclusions section of the report contains very severe criticism of the insurance industry. According to the Committee, “[i]nsurers appear to have been far more interested in establishing their future right to use genetic test results in assessing premiums, than in whether or not they are reliable or relevant.”<sup>103</sup> The report recognizes “the risk of adverse selection” and the principle that insurers “should have access to the same information as applicants.”<sup>104</sup> However, the Committee recommends serious limitations on the latter principle, by stating it is qualified by the conditions that information be relevant and reliable and that there be “no adverse consequences for society as a whole (for example, by discouraging people from taking tests).”<sup>105</sup> The Committee further states there is, at present, not sufficient evidence to support the relevance of genetic tests for the industry. It urges insurers

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<sup>99</sup>The Government response contains a reference to the notion of public interest, which is heavily criticized by McGleenan. See McGleenan, “Insurance, Genetics and the Law”, *supra* note 29 at 88.

<sup>100</sup>See U.K., Genetics and Insurance Committee, *Decision of the Genetics and Insurance Committee Concerning the Application for Approval to Use Genetic Test Results for Life Insurance Risk Assessment in Huntington’s Disease* (London: GAIC, 2000), online: U.K., Department of Health, Genetics and Insurance Committee <<http://www.doh.gov.uk/pdfs/gaichuntington.pdf>>.

<sup>101</sup>See “Genetics and Insurance”, *supra* note 88 at paras. 56-57.

<sup>102</sup>*Ibid.*

<sup>103</sup>U.K., Science and Technology Committee, “List of Recommendations and Conclusions” 5th Report, HC Paper 174 (London: Her Majesty’s Stationery Office, 2001), Recommendation 5, online: U.K. Parliament <<http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmselect/cmsctech/174/17403.htm>>.

<sup>104</sup>*Ibid.*, Recommendation 2.

<sup>105</sup>*Ibid.*

to publish more data to support their claims.<sup>106</sup> It does not endorse legislation that would prohibit insurers from using all genetic tests results, but recommends a voluntary moratorium of at least two years be agreed upon on the use of all positive genetic test results.<sup>107</sup> Finally, it recommends the approval of the use of the Huntington's test be reconsidered by a reformed Genetics and Insurance Committee, and the committee itself be reconstituted.<sup>108</sup>

The Human Genetics Commission, another governmental advisory committee set up in 1999 to replace the Human Genetics Advisory Commission and two other committees, endorsed several of the recommendations of this report in its "Comments to inform the Government response to the House of Commons report on Genetics and Insurance."<sup>109</sup> Reacting to these reports, the government and the industry jointly declared in November 2001 that the industry had voluntarily introduced a new five-year moratorium on the use of genetic tests for insurance. According to its terms, genetic tests can only be used if the Genetics and Insurance Committee has approved its use and the application is for life insurance coverage that exceeds \$500,000.<sup>110</sup>

The saga of the British moratoria and how they followed specific interactions between the government, industry and the public stands as exemplification of the political nature of this approach. The first moratorium was enacted after an explicit threat of state intervention by a committee of the House of Commons. One could argue that, politically, it was an appropriate and clever response of the industry in the midst of public and governmental debate. The speedy development and introduction of the *Code of Practice* was clearly an attempt to retain control over the initiatives and regulatory developments in this area and to appease the public and the government. The second moratorium was more clearly the result of a political move by the government, which had been instrumental in the development of a soft regulatory structure concerning genetic testing, but seemed to feel the public interest had not been adequately protected by the proposed—and according to some commentators, defensible<sup>111</sup>—approval structure. On the one hand, one can say the

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<sup>106</sup> *Ibid.*, Recommendation 3.

<sup>107</sup> *Ibid.*, Recommendation 29.

<sup>108</sup> *Ibid.*, Recommendations 17-18.

<sup>109</sup> U.K., Human Genetics Commission, *The Use of Genetic Information in Insurance: Comments to inform the Government response to the House of Commons report on Genetics and Insurance* (London: Human Genetics Commission, 2001), online: Human Genetics Commission <[http://www.hgc.gov.uk/business\\_publications\\_response\\_insurance.htm](http://www.hgc.gov.uk/business_publications_response_insurance.htm)>.

<sup>110</sup> Association of British Insurers, News Release 71/01, "Government Endorses a 5 Year Moratorium on Genetic Testing and Insurance 'Opportunity to Develop a Lasting Consensus' says ABI" (23 October 2001), online: Association of British Insurers <<http://www.abi.org.uk/newsreleases/default.asp?display=month&year=2001&month=10>>.

Reference provided by Kathleen Liddell.

<sup>111</sup> Knoppers, Godard and Joly comment on the Huntington's test controversy that "while the [Genetics and Insurance] Committee was accurate, the public was not ready for such transparency." With transparency, they refer to the fact that the same information can be obtained from family histories and that genetic tests, in other words, only confirm information already used by insurers, *supra* note 66 at 19.

United Kingdom experience highlights the precarious nature of a solution based on any moratorium, since the terms of the moratorium can so easily be changed and may be subject to continuous pressure. On the other hand, one could see it in a more positive light, as a reflection of the flexibility of such system in responding to public concerns.

In my view, it is clear that the evaluation system introduced through the use of the Genetics and Insurance Committee lacked regulatory firmness. The House of Commons Report on Genetics and Insurance revealed, for example, that insurers did not necessarily feel obliged to follow the recommendations of the Genetics and Advisory Committee and continued to have different policies with regard to the use of genetic test results. If public concern was so significant and the government considered this to be a public policy issue, it would have been appropriate to stimulate more extensive debate in Parliament and strengthen the regulatory system through a legislative scheme. This would force every interested party to be involved in debating a more definitive solution that would stand firmly once agreement on a strict regulatory scheme was obtained. A firmer legislative or regulatory scheme would also make the solution less subject to the volatility of changing public opinion and industry pressure tactics.

The example provided by the United Kingdom experience shows that one advantage of a moratorium is its flexibility. There is general agreement that genetic testing is still in its infancy and that underwriting information is still lacking. In this context, it is relatively easy to move the industry to enact a moratorium, since the industry has a real public advantage in doing so, and has little to fear at this time from the impact of such moratorium on the viability of the insurance system. This allows for further discussion and introduces a period of observation for both the insurance industry and the government, with time to gather statistical data and to think further about how to adjust the measures if problems appear. During this time, the lessons can be learned from regulatory and legislative approaches in other jurisdictions, where, presumably, not all are developing the same approach. At the same time, a moratorium on the use of the results of genetic testing is reassuring to research participants and those going for clinical testing.<sup>112</sup> It may remove the pressure on individuals to undergo genetic testing for the purpose of obtaining insurance, which, as I emphasized earlier, creates ethical concerns about undue influence on people in their decision to undergo potentially very burdensome clinical procedures. Obviously, a moratorium is not as reassuring as a firm legislative or regulatory enactment prohibiting the use of genetic testing for insurance. And when the respect of its terms is not obtained, it may undermine rather than establish public trust, as the United Kingdom example shows. It could also be misleading to consumers if a moratorium creates the impression of limitations on the use of genetic testing, which are shortly after abandoned by some or all of those involved in negotiating the moratorium.

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<sup>112</sup>This point is also stressed by Knoppers, Godard & Joly, *ibid*.

So, is there any value to the type of moratorium that merely confirms existing insurance practice, *i.e.*, that insurers will not impose genetic testing but will exercise their presumed right to ask for the results of genetic tests? Although such a moratorium will not reassure those who are afraid to undergo genetic testing because of potential insurance consequences, it can still serve a valuable public purpose. A firm and detailed statement of the extent to which insurers want to use genetic information and why they want to do so, accompanied with a firm commitment by the industry to respect this practice, clarifies the limits of insurers' interest in genetic testing. All too often, it is ill-understood how such information would be used and it is forgotten that insurers already offer various forms of insurance without much underwriting and for which genetic information will likely be ignored. A clarification of current practice with an explanation of how genetic testing fits within this practice may enhance understanding, which is a precondition for public trust, one of the bases on which insurance rests. Onora O'Neill suggests, in a book in which she discusses in detail the importance of trust, "insurers have been remarkably uninterested in the moves they need to make if their customers are to be able to reciprocate and place reasonable trust in them."<sup>113</sup> She goes on to state that insurers "would have to achieve far higher standards of transparency and non-deception in communication, by adhering to standards that could serve as a basis for judging whether particular products were set on a non-discriminatory basis."<sup>114</sup> The public announcement of a "moratorium," even if it may misleadingly suggest it constitutes a limitation on insurance practice, can be useful if it explains an approach that will be adhered to for a particular period of time. It is therefore appropriate, in the Canadian context, to call upon the Canadian insurance industry to develop a common approach to genetic testing and to affirm in a detailed proposal what forms of genetic testing it will not be using in the immediate future.

## 2. Industry Self-Regulation

In the discussion of the developments in the United Kingdom, I already mentioned an interesting example of detailed self-regulation, with the Association of British Insurers' enactment of a *Code of Practice*. Industry practices in many areas have been formalized by various national organizations through codes and standard practices. In several countries, insurance industry groups are working on specific codes of practice for the use of genetics.<sup>115</sup> These codes certainly are significant as they set a moral benchmark and create pressure on insurance companies, even those that may not be members of the organization that develops the practice. Insurance applicants can also benefit from the publicity resulting from the type of self-regulation proposed in the United Kingdom, since, if codes of practices

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<sup>113</sup> Onora O'Neill, *Autonomy and Trust in Bioethics* (Cambridge: Cambridge University Press, 2002) at 116.

<sup>114</sup> *Ibid.*

<sup>115</sup> Sandy Raeburn, "Clinical Aspects of Genetics and Insurance: The Development and Roles of Codes of Practice" in McGleenan, Wiesing & Ewald, *supra* note 14, 105 at 113.

are well-advertised and accessible to the public, they promote transparency and conformity.

If members of national organizations observe very faithfully the standards proposed by their organization, limits on the use of certain types of information may be possible without governmental regulation. Companies may be willing to accept limitations on certain forms of underwriting if they can be assured they will not be at a competitive disadvantage because of the restriction. National organizations may be helpful in promoting a common approach among competitors in the insurance market. The British example, where there was a mixture of self-regulation and governmental recommendations, also shows the serious limitations of self-regulation: if some decide not to abide by the rules, self-regulation fails. Much depends on the influence and impact of the organization enacting the code. Otlowski states convincingly that “reforms achieved in this way would not have the same capacity for enforcement and are therefore likely to be less protective of the interests of individuals who have undergone genetic testing.”<sup>116</sup> Moreover, any industry regulating itself will only go so far in hindering its own interests. Particularly in a situation where the public interest may be fundamentally opposed to that of the industry, mere self-regulation should not be relied upon.

The argument that the use of genetics in insurance ought not be limited since insurers have a commercial interest in selling insurance, not in excluding people from it, is ultimately also an argument about self-regulation. It suggests that if the market rules are respected and insurers do business as they have always done, both industry and the consumer will be better off. However, this obviously does not mean every consumer will be able to benefit from insurance. Legislative and regulatory intervention may be needed, not so much to protect the majority of potential insurance consumers, but to safeguard the few who are at risk for genetic diseases and may be affected by genetic discrimination.

I have discussed elsewhere why I believe that restrictions on the private insurance market are appropriate in light of important social policy issues, such as the avoidance of discrimination and the integration of people in the life of the community.<sup>117</sup> Both insurance and human rights law explicitly recognize the protection of the weaker contractual party and of the disadvantaged justify and even require limitations on contractual freedom. As I pointed out, several provisions in current insurance law recognize parties are in an unequal position. Some rules, for example the one in which the responsibility of applicants for failures to provide information is limited to information is relevant for underwriting, were imposed because of abuse of this position by some insurance companies. Even if most companies would do the right thing, legislation is needed for the few who refuse to observe industry standards. This is undoubtedly recognized in Canadian law.

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<sup>116</sup> *Implications of Genetic Testing*, *supra* note 39 at 57.

<sup>117</sup> See Lemmens, *Genetic Information and Insurance*, *supra* note 11 at c. 6.

There is no reason to object to industry policies and self-regulation, obviously, but self-regulation should not be relied upon as the sole mechanism of protection in this important area. As the Science and Technology Committee states, it can be doubted that “a trade organization funded by insurers to represent their own interests, is the right body to regulate the use of genetic test results.”<sup>118</sup> Others have also pointed out that the proposed review system for genetic testing under the *Association of British Insurers- Code of Practice* is undermined by a conflict of interest.<sup>119</sup>

### 3. Changes to insurance law

Various changes to insurance law can be envisaged to address issues related to genetic discrimination. I will first discuss the two major options for change, compare them with a status quo approach, and then briefly mention some more minor adjustments and exceptional approaches that have been proposed. The major options for change I focus on are: an absolute prohibition on the use of genetic test information; and the imposition of a “ceiling” amount of coverage under which genetic test results cannot be used.

#### 3.1. Absolute prohibition on the use of genetic testing

Prohibitions on the use of genetic testing have been introduced in various ways, offering variable degrees of protection against genetic discrimination. The *European Convention on Human Rights and Biomedicine* creates an obligation on the member states of the European Union to implement legislation that adheres to the provisions prohibiting discrimination on the basis of genetics (art. 11) and prohibiting genetic testing for purposes other than health care and research (art. 12). The prohibition of art. 12, restricting the use of genetic testing to the health care context, is the reason why this convention is discussed by Knoppers, Godard and Joly under the category of “the Therapeutic Approach.”<sup>120</sup> I will discuss this convention further under the Human Rights Approach, and will report there on the debate about whether these provisions leave room for an assessment of the reasonableness of the use of genetic information. This therapeutic approach is also reflected in a 1994 French law “*On respect for the human body*,” which introduced new provisions on genetic testing and DNA identification into the French Civil Code.<sup>121</sup> According to article 16-10, the genetic study of the characteristics of a person may be undertaken only for medical purposes or for scientific research. Restrictions on the conduct of genetic testing do not necessarily imply an absolute prohibition on the use of genetic information or test results “unless specified in the language of these or other provisions”, but they do prohibit insurers from imposing

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<sup>118</sup> Science and Technology Committee, *supra* note 103, Recommendation 23.

<sup>119</sup> See e.g. McGleenan, “Insurance, Genetics and the Law”, *supra* note 29 at 88.

<sup>120</sup> *Supra* note 66 at 11.

<sup>121</sup> *Loi n° 94-653 du 29 juillet 1994*, J.O., 30 July 1994, 11056, Gaz.Pal. 1994. 2e sem. Lég.576.

a genetic test for underwriting purposes. The importance of such a prohibition should not be underestimated, even if it would not ban the use of genetic test results already available, since one of the major concerns is that people will be pressured to undergo genetic testing which may occur without adequate counselling and support.

I will now focus on legislation that explicitly prohibits the use of genetic test information by insurers for underwriting purposes, as enacted in various countries, particularly in Europe. Among the clear examples are Austria,<sup>122</sup> Belgium,<sup>123</sup> Estonia,<sup>124</sup> Luxembourg,<sup>125</sup> Norway,<sup>126</sup> and Denmark.<sup>127</sup> In these countries, insurers can neither request genetic testing, nor use the test results of applicants that are already available in medical records. A distinction can be made in these statutes between those that introduce a broader absolute prohibition on the use of genetic information, and those that focus on insurance. The Austrian statute, for example, prohibits in general the imposition, requesting or use of genetic test by third parties, without specifically targeting the insurance context,<sup>128</sup> whereas the Belgian, Luxembourg and Danish statutes, for example, focus on insurance. I will now briefly explore the Belgian statute as an example of a strict prohibition introduced through changes to insurance law.<sup>129</sup>

The specific prohibition in the Belgian insurance law, the first legislative prohibition, was introduced in its new 1992 statute on insurance contracts, which replaced an older statute dating back to 1874.<sup>130</sup> It aimed at updating some aspects of Belgian insurance law.<sup>131</sup> One of the goals of the statute was to clearly emphasise contractual liberty and to give more power to patients in deciding what kind of medical information they want to give others. Physicians in Belgium had traditionally been reluctant to give medical information to patients, even if the latter

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<sup>122</sup>Federal Law of 1994 (BGB1. No. 510/1994) *regulating work with genetically modified organisms, the release and marketing of genetically modified organisms, and the use of genetic testing and gene therapy in humans* (the Gene Technology Law) and amending the *Product Liability Law*, (1995) 46 Int. Dig. Health Legis. 42, s. 67.

<sup>123</sup>*Wet 25 juni 1992 op de landsverzekeringsovereenkomst*, B.S. 20 August 1992.

<sup>124</sup>*Human Gene Research Act* (2001), cited in *Genetic Information and Testing*, *supra* note 66 at 22-23.

<sup>125</sup>*Loi du 27 juillet 1997 sur le contrat d'assurance*, cited in Knoppers, Godard & Joly, *supra* note 66 at 15.

<sup>126</sup>*Law No. 56 of 5 August 1994 on the medical use of biotechnology*, (1995) 46 Int. Dig. Health Legis. 51, s. 6-7.

<sup>127</sup>*Act No. 413 of July 1997 to amend the insurance agreement act and act on the supervision of company pension funds*, cited in *Genetic Information and Testing*, *supra* note 66 at 22.

<sup>128</sup>For a discussion of the implications of the Austrian statute in the context of insurance, see Gertrud Hauser & Astrid Jenisch, "The Implications of Genetic Regulation for Insurance: The Austrian Experience" in McGleenan, Wiesing & Ewald, *supra* note 14, 97.

<sup>129</sup>I am indebted to Sandra De Waele and, more recently, to Caroline Van Shoubroeck, for providing me with interesting sources on Belgian insurance law. The following discussion of the Belgian statute is an updated version of a discussion in Lemmens & Bahamin, *supra* note 52 at 242-245.

<sup>130</sup>*Supra* note 123.

<sup>131</sup>Applicants' duty to declare relevant information to insurers and the extent of professional secrecy for physicians were, for example, adapted.

explicitly request it for insurance purposes.<sup>132</sup> In these contexts, it is surprising that the new law also introduces a strict prohibition on the transfer of one particular form of medical information.

According to some commentators,<sup>133</sup> the amendment may have been inspired by a recommendation of the Committee of Ministers of the European Council,<sup>134</sup> made around the same time, which recommended member states enact regulations that prohibit insurers from using the results of genetic testing for underwriting purposes.<sup>135</sup>

The duty of disclosure as originally drafted in the Belgian statute was generally similar to that in Quebec law. According to article 5 of the new Belgian law, applicants must declare all circumstances they could reasonably expect to influence the assessment of risks by insurers. They have no obligation, however, to declare facts insurers either know or should know. If applicants do not answer questions on medical questionnaires and insurers conclude the contract nevertheless, the latter may not nullify the contract (except in cases of fraud). During discussions for a parliamentary commission, the following clause was added to article 5: "Genetic data may not be declared."<sup>136</sup> This clause does more than relieve applicants of their obligation to disclose genetic data, which an earlier amendment did.<sup>137</sup> Applicants are actually *prohibited* from submitting the results of genetic testing to insurers, whether these results are positive or negative. The parliamentary commission's report mentions this prohibition was considered necessary to protect the privacy rights of family members.<sup>138</sup> Furthermore, the fact that even beneficial genetic information may not be declared makes it impossible to bypass a mere prohibition against requesting genetic test data. In the latter case, insurers could have circumvented the statute by offering lower premiums to those who voluntarily submit genetic test data.<sup>139</sup>

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<sup>132</sup> See Dominique Freriks, "De verzekeringwet van 25 juni 1992 en het medisch beroepsgeheim" (January-February 1995) *Vlaams Tijdschrift voor Gezondheidsrecht* 1993.

<sup>133</sup> See Herman Cousy *et al.*, eds., *Artikelsgewijze Commentaar Verzekeringen* (looseleaf) (Antwerpen: Kluwer, 2001) at 58 [*Artikelsgewijze Commentaar*].

<sup>134</sup> Council of Europe, Committee of Ministers, *Recommendation R (92) 3*, online: Council of Europe <<http://www.coe.fr/cm/ta/rec/1992/92r3.htm>>.

<sup>135</sup> See *ibid.*, Principle 7: "Insurers should not have the right to require genetic testing or to enquire about results of previously performed tests, as a pre-condition for the conclusion or modification of an insurance contract."

<sup>136</sup> "Genetische gegevens mogen niet worden meegedeeld" [translated by author].

<sup>137</sup> See Herman Cousy & Geert Schoorens, eds., *De nieuwe wet op de landverzekeringsovereenkomst. Parlementaire voorbereiding van de Wet van 25 juni 1992 en van de Wijzigende Wet van 16 maart 1994* (Antwerpen: Kluwer, 1994) at 82-85. This work gives an overview of the parliamentary debates on the new insurance law.

<sup>138</sup> *Ibid.* at 83.

<sup>139</sup> Herman Nys, "Van afkomst naar toekomst? Juridische grenzen van erfelijkheidsonderzoek bij verzekeringen?" (1992) 299 *Bulletin des Assurances - Tijdschrift voor Verzekeringen* 209 at 215 ["Van afkomst naar toekomst?"].

Insurers may require applicants to undergo medical examinations by physicians of their choice. However, the law explicitly prohibits physicians from using genetic testing in medical examinations for insurance purposes. Article 95 states these examinations may be based only on medical history and the actual state of health, not on genetic tests to determine the future state of a person's health.<sup>140</sup>

The law does not stipulate specific penalties for violations. Physicians could be held liable in tort for the consequences of violating the law, or they could be sanctioned under the criminal law and/or under their professional code. Performing a genetic test for insurance purposes would be a violation of physicians' professional duty.

Although this law was introduced in 1992, no Belgian court seems to have been confronted with cases involving the inappropriate use of genetic testing for insurance.<sup>141</sup> One might conclude from this that the ban has been generally accepted, but this is not necessarily the case since the insurance industry was not dependent on genetic tests at that time. Although the prohibition does not seem to have undermined the insurance industry in Belgium, it would be incorrect to state that this type of legislation provides adequate protection while at the same time providing an acceptable limit on insurance practice.

The provisions on genetic testing have been variously criticized by commentators for their vagueness, their absoluteness, and the insufficient protection they offer.<sup>142</sup> The problems occur on two levels: first there is the more technical question of what the statute actually prohibits, and second, there are concerns about the fairness of the protective scheme.

Nothing in the law defines "genetic data" or "techniques of genetic research that are used to determine the future state of health."<sup>143</sup> Commentators have indicated it is not clear whether the prohibition includes genetic information that has been discovered by chance in the course of other medical research.<sup>144</sup> Defining genetic information in detail is very important, since new developments in research

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<sup>140</sup> *Supra* note 125, art. 95: "...Het medisch onderzoek, noodzakelijk voor het sluiten en het uitvoeren van de overeenkomst, kan slechts steunen op de voorgeschiedenis van de huidige gezondheidstoestand van de kandidaat-verzekerde en niet op technieken van genetisch onderzoek die dienen om de toekomstige gezondheidstoestand te bepalen."

<sup>141</sup> No cases are mentioned in Cousy *et al.*, *Artikelsgewijze Commentaar*, *supra* note 135. Caroline Van Schoubroeck, Faculty of Law, K.U. Leuven, contributor to this authoritative loose leaf publication on Belgian insurance law, confirmed the absence of any important cases on these provisions (personal communication, July 2002).

<sup>142</sup> See in particular Nys, "Van afkomst naar toekomst?", *supra* note 139 at 217; Nathalie Jeger & Patrick Cauwenbergh, "Individuele Levensverzekeringen 'Overlijden' en Erfelijkheidsonderzoek: Een Kritische Analyse van de Artikelen 5 en 95 van de Wet van 25 Juni 1992 op de Landsverzekeringsovereenkomst" (1996-1997) *Tijdschrift Gezondheidsrecht/ Revue du Droit de la Santé* 239, in particular at 241-244. See also Cousy *et al.*, *Artikelsgewijze Commentaar*, *supra* note 133 at 57-60.

<sup>143</sup> The terms of the statute were translated by the author.

<sup>144</sup> See Cousy *et al.*, *supra* note 133 at 58; and Nys, "Van afkomst naar toekomst?", *supra* note 139 at 217.

may make testing on derived products such as proteins much more important. At the same time, traditional insurance practices that indirectly reveal genetic information, such as asking questions about a person's family history of diseases, are not explicitly prohibited in this statute. One could claim they fall under the notion of "genetic data," but there are problems with expanding the notion of genetic data to include family history. Many, if not all diseases have a genetic component. Personal characteristics, such as sex, age, height, weight, could also fall under an expanded notion of genetic information.

However, the statute clearly does not intend to prohibit the use of those types of personal information that have always been used for underwriting purposes. Prohibiting this would basically mean insurers are no longer allowed to ask questions of insurance applicants, which would fundamentally change the nature of the insurance contract. Reading the reference in article 5 in conjunction with article 95 supports a restrictive interpretation of genetic data as encompassing solely information resulting from genetic testing. The statute does not, in other words, affect the insurance practice of obtaining genetic information by asking questions about family histories. Although there is no caselaw on genetic testing, genetic information has still been used after 1992. Genetic information can be found more easily through questionnaires than tests. Information about the more determinant genetic diseases, which are at this time the ones that are of most interest for underwriting purposes, can easily be derived from family histories. Most other genetic tests do not offer very precise risk information and are therefore of less interest to insurers.

In the long run, the prohibitions of Belgian law might prove unenforceable. Over time, it will probably become increasingly difficult to distinguish genetic from other medical information. Genetic testing will become an ordinary diagnostic tool, integrated within medical files, and often intrinsically linked to the other types of health information that can still be used by insurers.

Some other issues of interpretation are also worth mentioning briefly since they illustrate some of the pitfalls associated with such legislation. Herman Nys, as well as Nathalie Jeger and Patrick Cauwenbergh, point out that the prohibition against revealing genetic information to insurers is contained in a provision dealing exclusively with the insurance applicant. This, in their view, could be interpreted as allowing the others who are to be insured under an insurance contract to reveal genetic information, which would clearly undermine the goal of the statute, *i.e.*, to protect the consumer and the confidentiality of family information.<sup>145</sup> If protection against the use of genetic information is warranted, these provisions must be carefully crafted so genetic information cannot be obtained indirectly, *e.g.*, through information provided by others insured and by family members.

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<sup>145</sup> See Jeger & Cauwenbergh, *supra* note 142 at 242;

Aside from drafting issues, there is a more profound problem with this approach, related to the absolute character of the prohibition. During the parliamentary debate, one senator argued article 95 was unfair because non-genetic diseases must still be declared.<sup>146</sup> Those who are informed of a non-genetic disease would be penalized as a result of being informed, but those with genetic diseases would not be obliged to declare them. The senator used high cholesterol level as an example of a non-genetic factor that is already taken into account by insurers. The example may not be completely appropriate “since high cholesterol has been associated with genetic factors”<sup>147</sup>, but he had highlighted one of the core problems in the statute. After all, some diseases, now considered non-genetic, will likely some day be considered genetic. Diseases can have genetic, non-genetic, or unidentified causes. Women who have a breast cancer gene, for example, would not be obliged to declare it; but those who have been treated for non-genetic (or “not-yet-genetic”) breast cancers would be obliged to do so – even if these cancers have been treated successfully.

The senator’s comment goes to the heart of the debate about the equity of under-inclusive provisions. Although, as I have discussed elsewhere, there is reason to be concerned about the social implications of the use of genetics outside the health care context, genetics amplifies existing concerns rather than creating entirely new ones.<sup>148</sup> While developments in genetics may make it more necessary than ever to enhance protection for those who are particularly affected by future health risks, it seems contrary to our common sense of fairness to offer special protection to a person who is affected by a “genetic” risk, while allowing discrimination against a person who has another, comparable form of health risk or suffers from a similar disease that has not yet been declared genetic. Otlowski also notes this concern:

... one difficulty with a blanket prohibition preventing insurers from using any genetic test information in their risk assessment calculations is that it unduly favours individuals who suffer from genetic conditions over those whose condition is of a non-genetic nature.<sup>149</sup>

The Belgian prohibition against voluntary submission of genetic test results to insurers has also been criticized since it makes it impossible for applicants to obtain a better premium by showing a negative test result. The logic of the provision is clear: if insurers are allowed to offer a lower premium or another financial incentive to those who indicate by voluntarily submitting genetic test results that they are at lower risk for premature death or disease, the prohibition could easily be circumvented.

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<sup>146</sup> Cousy & Schoorens, *Artikelsgewijze Commentaar*, *supra* note 137 at 306.

<sup>147</sup> *Ibid.*

<sup>148</sup> See Lemmens, “Selective Justice,” *supra* note 5, in particular at 369-380; Trudo Lemmens & Lisa Austin, “The Challenges of Regulating the Use of Genetic Information” (2001) 2:3 ISUMA, Can. J. Policy Research 26.

<sup>149</sup> *Implications of Genetic Testing*, *supra* note 39 at 53.

The absolute prohibition also leads to the unfortunate situation that those who are already discriminated against by insurers' use of family history of disease cannot escape their high risk status by indicating they do not carry a genetic predisposition that is prevalent in the family. This has serious consequences for, for example, people with a family history of Huntington's disease. They are often excluded from life insurance coverage or have to pay an exorbitant premium for it. But even if they test negative for Huntington's disease, they cannot, according to article 5, submit this test result to obtain a standard premium. This result goes directly against the aim of the legislative provisions, i.e., to protect against genetic discrimination, since it does not allow these individuals to remove the effects of existing genetic discrimination and to reintegrate into the community of "normal risk" contractors.

As for the economic feasibility of the absolute prohibition introduced under Belgian law, there is to my knowledge no indication the insurance industry in Belgium has been seriously affected by adverse selection. However, this may very well be on account of the fact that the protection aimed at by the statute has not been realized. Insurance practice does not seem to have been significantly affected by the legislative change and insurance companies have continued to use family histories in their underwriting practices. The Belgian statute gives us, in other words, no evidence about the impact of an absolute prohibition, while at the same time providing little protection against genetic discrimination. A broader prohibition of the use of any genetic information, including family history, would almost certainly create more risk of serious adverse selection.<sup>150</sup> It also remains to be seen whether future developments in genetics, particularly the commercial development of home kits for genetic testing, could increase the phenomenon of adverse selection, thereby creating problems for the industry.

Finally, the absolute prohibition has also been criticized on moral grounds. Jeger and Cauwenbergh distinguish "elementary" from "luxury" insurance contracts and argue that only the former deserve the protection targeted by the Belgian statute.<sup>151</sup> They discuss the two types of contracts separately, providing interesting criteria to determine the nature of an insurance contract<sup>152</sup> and also propose *de lege ferenda* how a legislator could treat these two types of contract separately. Herman Nys likewise suggests the use of genetics should only be prohibited for insurance contracts under a specified amount and the law should explicitly outlaw questioning applicants about family histories of genetic diseases for such basic insurance contracts, thus supporting a "ceiling" approach, which I discuss immediately below.<sup>153</sup>

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<sup>150</sup> *Ibid.* at 52.

<sup>151</sup> *Supra* note 142 at 244-253.

<sup>152</sup> I will discuss these below. See text accompanying notes 170-172.

<sup>153</sup> Nys, "Van afkomst naar toekomst?", *supra* note 139 at 216.

### 3.2. Ceiling Approach

The ceiling approach was proposed as early as 1989 by a report of the Health Council of the Netherlands on the social and ethical problems presented by genetics.<sup>154</sup> As a result of this report, the Dutch insurance industry agreed in 1990 to restrict the use of genetic information in accordance with many recommendations of the report.<sup>155</sup> Under the terms of this moratorium, insurers could not impose genetic testing as a precondition for insurance. Neither could they request the disclosure of genetic information for insurance contracts under a specified ceiling. The ceiling was established at D.Fl. 200,000 (about CAD 140,000) for life insurance and at D.Fl. 40,000 for disability insurance. The moratorium was initially planned for a period of five years, after which the insurance industry would evaluate the situation. It later extended the moratorium for an undetermined period.<sup>156</sup> But again illustrating the precariousness of such “voluntary” moratoria, the terms of the moratorium continued to be challenged. On 14 January 1995, at a symposium on “Predictive Genetic Research,” the Dutch Health Minister at that time, Ms. Borst-Eilers, argued the insurance industry’s policy of excluding people with family histories of genetic diseases violated the spirit of the moratorium.<sup>157</sup> Despite a government statement sent to Parliament the previous year, she did not exclude governmental initiatives to regulate the use of genetic information by insurers.<sup>158</sup>

It took several years before parliamentary initiatives resulted in legislation dealing with the use of genetics for insurance purposes. The legislation that was finally established integrates, to a large extent, the terms of the moratorium into a legislative framework. The Medical Examination Act,<sup>159</sup> which came into force in 1998, introduces a ceiling coverage limit, which varies depending on the nature of the insurance policy.<sup>160</sup> For life insurance policies, the limit is D.Fl. 300,000, (about CAD 210,000) while the limit for disability insurance is set at D.Fl. 60,000 (about CAD 42,000). These amounts are to be adjusted every three years according to the

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<sup>154</sup> Health Council of the Netherlands, *Heredity, Science and Society: On the Possibility and Limits of Genetic Testing and Gene Therapy* (The Hague: Health Council of the Netherlands, 1989).

<sup>155</sup> J.K. Gevers, “Genetic Testing and Insurance” (1992) 11 *Med. & L.* 541 at 543.

<sup>156</sup> “Verzekeraars verlengen moratorium erfelijkheidsonderzoek” (December 31, 1994) *De Staatscourant* 1. Also reported in Science and Technology Committee, “The Science and Its Consequences”, *supra* note 89 at 78.

<sup>157</sup> “Borst-Eilers: Genetisch Onderzoek geen zaak van deskundigen alleen” (January 17, 1995) *De Staatscourant* 2.

<sup>158</sup> In this statement, it had accepted the refusal to provide insurance in cases of family history of genetic disease. The mortality risk and the related risk of adverse selection had been invoked to justify that point of view. *Het Gebruik van voorspellend medisch onderzoek bij keuringen*, Tweede Kamer, vergaderjaar (1993-1994), 23 612, nr. 1-2; discussed by Henriette D.C. Roscam Abbing, *supra* note 38 at 160.

<sup>159</sup> *Wet van 5 juli 1997, houdende regels tot versterking van de rechtspositie van hen die een medische keuring ondergaan* (Staatsblad 1997: 365).

<sup>160</sup> For a detailed discussion of the Act in its historical context, see Rob Salomons, “Erfelijke Gegevens en Verzekering” in Centre for Risk and Insurance Studies, Katholieke Universiteit Leuven, H. Cousy *et al.*, eds., *Liber Amicorum Hubert Claassens. Verzekering: Theorie en Praktijk* (Antwerp: Maklu, 1998) 165. The statute is also briefly discussed in Laurie, *supra* note 81 at 149-150; and Otlowski, *Implications of Genetic Testing* *supra* note 39 at 54.

cost-of-living index. An interesting feature of the Act is that it does not focus exclusively on genetics, but rather on certain types of medical examination.<sup>161</sup> Under the statute, insurers are never allowed to request a genetic test as a precondition for insurance. Other restrictions only apply to insurance contracts under the ceiling amount. For contracts with coverage under the ceiling, applicants should not be asked whether they suffer from a hereditary, untreatable or serious medical condition unless they already have symptoms of the disease. In addition, insurers cannot ask questions about such conditions among family members, even if a family member has symptoms of the disease. Applicants should not be asked to disclose genetic test results for these basic contracts. The prohibition introduced in this legislation for the basic contracts under the ceiling is more widely encompassing than is the prohibition under Belgian law, since it includes the use of family history of hereditary diseases. This type of ceiling system thus combines an absolute prohibition to apply to what one could call basic contracts, with contractual freedom limited only by provisions for no obligatory genetic tests above a certain amount of coverage.

The ceiling approach can be found in other jurisdictions, such as Sweden and the United Kingdom, where it has been introduced on the basis of a voluntary moratorium. It has been supported by many commentators.<sup>162</sup> Otlowski, for example, calls it a “meritorious approach.”<sup>163</sup> Various Canadian reports have also commended it, one as early as in 1991.<sup>164</sup>

What are the advantages of the ceiling approach? First, in terms of feasibility, McGleenan has pointed out that a no-questions-asked, basic insurance coverage “is in effect a relatively common practice in the insurance industry.”<sup>165</sup> Insurance companies in many countries, including Canada, often only start using detailed underwriting for contracts above a certain amount. Genetic testing is unlikely to be introduced for basic contracts anyway, so it should not constitute a major problem to implement this as a legal obligation. Insurers already offer such contracts and they will have the comfort of knowing their competitors are submitted to the same restrictions. Is there then any advantage in a legislative imposition of common insurance practice? One advantage is that of certainty and of reassuring the public

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<sup>161</sup> Laurie seems to ignore this fact when he discusses a controversy which erupted after insurers in the Netherlands were accused of violating the law by using cholesterol level testing. “If this is an infringement of the law,” he asks rhetorically, “then is it meaningful to continue to view that law as dealing solely with genetic information?”, *ibid.* at 150. But, in fact, the statute is not solely about genetics.

<sup>162</sup> See e.g. Otlowski, *Implications of Genetic Testing*, *supra* note 39 at 54, Laurie, *ibid.* at 148; Nys, “Van afkomst naar toekomst?”, *supra* note 139 at 216; Simon, *supra* note 66 at 149; Knoppers, Godard & Joly, *supra* note 66 at 18; Sandberg, *supra* note 79 at 1557-1558.

<sup>163</sup> *Ibid.* at 57.

<sup>164</sup> See Bartha Maria Knoppers, *Human Dignity and Genetic Heritage*, Study Paper, Protection of Life Series (Ottawa: Law Reform Commission, 1991) at 50; Science Council of Canada, *Genetics in Canadian Health Care*, Report 42 (Ottawa: Minister of Supply and Services, 1991) at 80; and, more recently, Ontario Law Reform Commission, *supra* note 36 at 127, 231; Ontario, Provincial Advisory Committee on New Predictive Genetic Technologies, *Genetic Services in Ontario: Mapping the Future* (Toronto: Queen’s Printer for Ontario, 2002) at 27.

<sup>165</sup> McGleenan, “Insurance, Genetics and the Law”, *supra* note 88 at 80.

that there is entrenched protection against genetic discrimination and some guaranteed access to insurance. It ensures such common practice is not changed later, when the alternative appears to be more profitable.

The fact that basic policies already exist is related to the second advantage of a ceiling approach, which is related to the concern for adverse selection. Adverse selection is “any increased tendency, on the part of people at higher risk, to buy insurance.”<sup>166</sup> Angus Macdonald distinguishes two different ways in which adverse selection can manifest itself in life insurance: a greater likelihood of buying insurance; and a tendency to take higher insurance coverage among those people who know they are at higher than average risk.<sup>167</sup> Adverse selection is likely to create more serious problems if it inspires people at high risk for genetic diseases to take higher than average insurance coverage.<sup>168</sup> By putting a cap on the coverage, adverse selection is limited and the possible costs of the more limited adverse selection that could occur under the ceiling can likely be integrated into small premium increases across the board. The ceiling approach thus provides some form of protection while preventing significant adverse selection.

A more principled advantage is related to the concern about fairness. While limitations to contractual freedom are fundamentally acceptable to ensure access to particular goods, they must be in proportion to the nature of the good.<sup>169</sup> For example, the small increase in premiums for all policy holders, to compensate for the limited adverse selection which could result from a ceiling approach, could be defended as being proportional when it provides general access to basic insurance. The same cannot be said about significant premium increases that allow some individuals who, to obtain excessively high insurance contracts for the benefit of their dependents, attempt to translate their high risk status into a profitable market item. The distinction between basic or “elementary” and “luxury” insurance contracts has been made by many authors.<sup>170</sup> While it could be argued that limited life insurance has become a basic social good, in particular when it is connected to other contracts, such as loans and mortgages, the same cannot be said for insurance contracts with very high coverage.<sup>171</sup> The Ontario Law Reform Commission

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<sup>166</sup> A. S. Macdonald, “Human Genetics and Insurance Issues” in Iain Torrance, ed., *Bio-ethics for the New Millennium* (Edinburgh: St. Andrew Press, 2000) 25 at 27.

<sup>167</sup> *Ibid.*

<sup>168</sup> In the same vein, Knoppers, Godard & Joly, *supra* note 66 at 18.

<sup>169</sup> For a more detailed development of this argument, see Lemmens, “Selective Justice,” *supra* note 5, in particular at 385-388; Lemmens, *Genetic Information and Insurance*, *supra* note 11, at chapter 6.

<sup>170</sup> For a detailed discussion, see Jeger & Cauwenbergh, *supra* note 142 at 244-53. See also Knoppers, Godard & Joly, *supra* note 65; Otlowski, *Implications of Genetic Testing*, *supra* note 39 at 57-58; Sandberg, *supra* note 79 at 1557. But see Otlowski, “Resolving the Conundrum,” *supra* note 73 at 211, where she states, without any distinction based on the level of coverage, that life and related forms of insurance are “undoubtedly a ‘social good’”.

<sup>171</sup> Jeger & Cauwenbergh point out, however, that the “luxurious” nature of insurance coverage also depends on the financial needs it aims to fulfill. Indeed, while \$200,000 in coverage may be luxurious when the beneficiary is a working partner with significant personal assets, it may be seen as basic when it aims at providing some financial security to a surviving family of five young children. *Ibid.* at 247.

suggests this when it asks: “[M]ight we not consider access to and availability of a basic minimum of life insurance as an entitlement, rather than simply as a privilege, since it is often a prerequisite for other economic ‘goods’ such as credit, mortgages and so on?”<sup>172</sup>

The ceiling approach guarantees access to some form of insurance while recognizing that not all insurance contracts ought to be submitted to a protective regime. However, as I pointed out, fairness issues are also raised by the fact that some people can benefit from the prohibition below the ceiling, while others who are submitted to the same risks on the basis of similar characteristics (health risks) remain excluded.<sup>173</sup> The Dutch statute is also interesting in that respect, since it focuses not only on genetic susceptibility but also on other health risks that are now used by insurers, such as family history of disease. In the Canadian context, it would be more circumspect for provincial legislators to develop legislation that does not single out genetics for prohibition. This would help to avoid challenges based on violations of the *Charter*’s equality guarantee.

The determination of the ceiling amount is another point that merits some discussion. The Dutch statute sets a specific fixed monetary ceiling for each kind of insurance. But this is not the only option. Per Sandberg points out that “[t]he limit can be set appropriately to the applicant’s social and financial circumstances, or it can be a uniform one.”<sup>174</sup> In fact, when it comes to life insurance, it is often not so much the applicant’s own financial needs that are at stake (unless insurance coverage is needed to obtain another good), but those of the applicant’s beneficiaries. One could argue that the setting of a fixed limit actually disadvantages those who do not have significant assets to leave for their children, but wish to provide at least some basic security in case they die prematurely.

Jeger and Cauwenbergh note this and recommend several criteria be introduced in legislation to determine in specific cases what constitutes an “elementary” life insurance contract.<sup>175</sup> First, they distinguish between two forms of basic contracts: those that serve as a means to access other important goods and those that fulfill the same role as the “*obligation alimentaire*” of the civil law: the obligation of mutual support in the family. For this second category of insurance contracts, they suggest the following three criteria be taken into consideration: the relationship between the insured and the beneficiary (e.g., is there an obligation of mutual support?); the need of the beneficiary and how it relates to the sum insured; and the financial situation of the insured (are there other financial assets?).

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<sup>172</sup> *Supra* note 164 at 106-07.

<sup>173</sup> This is pointed out by Otlowski, *Implications of Genetic Testing*, *supra* note 39 at 60. She rejects, however, the idea of a guaranteed level of life insurance as unrealistic.

<sup>174</sup> *Supra* note 79 at 1557. In the same vein: Otlowski, *Implications of Genetic Testing*, *ibid.* at 61.

<sup>175</sup> *Supra* note 142.

From the perspective of justice, adapting the ceiling in light of these criteria makes sense. Indeed, if the idea behind a guaranteed basic insurance is to provide access to a needed good, the determination of financial need certainly depends on the investigation of particular circumstances. However, there may be significant practical problems related to the implementation of this approach.<sup>176</sup> It may be very hard to compare different people's financial assets and to develop an efficient administrative structure that can conduct such comparative assessments. On a more fundamental level, it also seems we are definitely leaving, with such an individual needs-based approach, the sphere of the market and entering the sphere of state-organized support. It is hard to imagine how market mechanisms could deal with this type of inquiry, although it merits further exploration.

The ceiling approach could arguably be seen as a limited interference with the market to ensure that everyone has some access to a good that, although appropriately situated within the market sphere, is important for purposes of membership and participation in social life. This complex needs-based approach, however, may be better left to a state supported welfare system where distribution is done on the basis of need.

Criteria to determine the financial needs of beneficiaries could be used, perhaps, when adjudicating insurance cases. If adverse selection becomes a serious problem even under a ceiling system, due to people who are at significant genetic risk taking out the maximum insurance allowed, one way of limiting its impact would be to introduce a system of adjudication. Under this system, when an applicant or an insured person dies as a result of a disease that had been predicted by a genetic test known to the applicant, an independent committee of adjustors could take criteria of dependence and need into consideration to determine an appropriate amount of coverage.<sup>177</sup> This could be justified on the basis of fairness principles, but it remains to be seen whether it would be practically possible to introduce this system into existing insurance law.

A ceiling approach is therefore the preferred option. The height of the ceiling is an issue that can only be discussed *in concreto*, with consideration of specific economic parameters such as current insurance practice and concerns about adverse selection in a specific insurance system. Sandberg points out, for example, that the average individual life insurance contract in a given country is an important indication of what constitutes "needed" insurance there.<sup>178</sup> A very important consideration is, in my view, the availability of other social support mechanisms,

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<sup>176</sup>Otlowski simply argues that "[a] fixed ceiling would be easier to apply and would provide more certainty and predic[t]ability for the insurance industry." See Otlowski, *Implications of Genetic Testing*, *supra* note 39 at 61.

<sup>177</sup>The possibility of proportional reduction of insurance coverage, rather than *de lege* annulment *ab initio* of the contract, is not new. McGleenan discusses how the French insurance Code allows for a proportional reduction of the claim in cases of good faith lacunae in the disclosure: McGleenan, "Insurance, Genetics and the Law", *supra* note 88 at 79.

<sup>178</sup>Sandberg, *supra* note 79 at 1557.

since the justification for the provision of basic insurance coverage is its classification as a basic social good.

There are also practical issues that have to be considered in developing a ceiling approach in insurance law. Basic insurance contracts have to be limited by regulation. Provisions would have to be made to prevent individuals at high risk for genetic disease from buying multiple basic insurance contracts, thus creating the very adverse selection problem the ceiling approach tries to prevent.<sup>179</sup> To deal with this issue, McGleenan and Wiesing suggest the creation of an information-sharing system, or a provision by law that non-disclosure of other basic insurance coverage renders subsequent contracts void.<sup>180</sup>

Another point raised by Sandberg<sup>181</sup> is the fact that regulation may be needed to prevent some insurance companies from focussing on insurance contracts with coverage above the ceiling, which could be offered at a lower premium than no-questions-asked insurance. By doing so, they may attract the people who are at lower genetic risk, which will distort the market and create, once again, the adverse selection the ceiling approach is designed to avoid. Insurers may have to be obliged to offer a balanced insurance portfolio, with regulation of their prices.

### **3.3. Other Proposals Related to Insurance Law**

Minor adjustments to insurance law could also be introduced that may address some concerns about the application of insurance law in the context of genetic risks. The disclosure obligations of the insurance applicant, which are based, in common law, upon the perspective of the reasonable insurer, could be shifted to recognize the difficulty for applicants in appreciating what a reasonable insurer would want to know. If the aim of disclosure obligations is to avoid adverse selection, then looking at how an applicant understands his or her risk of developing a disease is reasonable. It makes sense to introduce the approach supported in Quebec and in other jurisdictions<sup>182</sup> where applicants have a duty to declare what they think would be relevant for the determination of their premium. Courts could then more clearly take into consideration the level of knowledge and understanding of the particular applicant. In light of the complexity of genetic information, this seems reasonable.

Another approach, discussed by McGleenan, is found in the French Insurance Code.<sup>183</sup> French insurance law reduces the harshness of the sanction in cases of good faith non-disclosure of material risks, by reducing the coverage in proportion

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<sup>179</sup> *Ibid.*

<sup>180</sup> McGleenan & Wiesing, *supra* note 67 at 119.

<sup>181</sup> Sandberg, *supra* note 79.

<sup>182</sup> In the same vein, McGleenan & Wiesing, *ibid.* at 120-121.

<sup>183</sup> McGleenan, "Insurance, Genetics and the Law", *supra* note 88 at 79

to the increase in premium the insurer would have charged had she known about the risk factor.

Other minor changes should be considered. To safeguard confidentiality and to prevent family members from obtaining information they would not want to know through the process of applying for insurance, provisions could be introduced, stating explicitly that genetic risk information can only be used for the individual applicant's underwriting, but not for the underwriting of family members. Additional privacy rules should address some of the specific privacy concerns raised by genetics, either in insurance law or in general privacy legislation. A discussion of the latter exceeds the scope of this article, but it is increasingly recognized that the potential implications of genetics in different areas of social life make it more important than ever to develop a comprehensive regulatory scheme to safeguard the privacy of health information.<sup>184</sup>

#### 4. Human Rights Approach

Genetic discrimination has also been addressed through what has been described as "human rights approaches."<sup>185</sup> One can distinguish two separate types of initiatives that can be classified as such. The first type deals with those formal declarations by international organizations that invoke the language of human rights but do not have strict legal force. Under this initiative one can mention the 1997 *Universal Declaration on the Human Genome and Human Rights* by UNESCO,<sup>186</sup> the 2000 *Charter of Fundamental Rights of the European Union*,<sup>187</sup> or other initiatives that attempt to develop specific guidelines related to genetics, invoking also human rights language, such as the 1998 *Statement on DNA Sampling: Control and Access* by the Ethics Committee of the Human Genome Organization,<sup>188</sup> and the *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services* of the World Health Organization, published in 1999.<sup>189</sup>

The UNESCO declaration states, for example, in article 6 that "[n]o one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and

<sup>184</sup> See generally Laurie, *supra* note 81. For a shorter discussion, see Lemmens & Austin, *supra* note 148.

<sup>185</sup> See e.g. Knoppers, Godard & Joly, *supra* note 66 at 8-11.

<sup>186</sup> *Universal Declaration on the Human Genome and Human Rights* (1997), online: United Nations Educational, Scientific and Cultural Organization <[http://www.unesco.org/human\\_rights/hrbc.htm](http://www.unesco.org/human_rights/hrbc.htm)>.

<sup>187</sup> E.C., *Charter of Fundamental Rights of the European Union* [2000] O.J. C. 364/01, online: Council of the European Union <<http://ue.eu.int/df/default.asp?lang=en>>.

<sup>188</sup> Human Genome Organization Ethics Committee, "Statement on DNA Sampling: Control and Access" (February 1998), online: Human Genome Organization Ethics Committee <<http://www.hugo-international.org/hugo/sampling.html>>.

<sup>189</sup> World Health Organization, *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services*, WHO/HGN/GL/ETH/98.1, (1999), online: World Health Organization <<http://www.who.int/ncd/hgn/hgnethic.htm>>.

human dignity.”<sup>190</sup> Knoppers, Godard and Joly point out that the European Union’s declaration mirrors this provision in prohibiting discrimination based on “genetic features.”<sup>191</sup>

These international initiatives are to be welcomed as important statements of principle. The impact of these declarations and guidelines may depend on the moral authority and status of the organizations enacting them, but they reflect a common commitment of the international community to make sure that the results of genetic research, aimed at the amelioration of the human condition, are not used to the detriment of particular individuals. The value of these statements lies in the fact they draw attention to the potential deleterious impact of genetics on human rights and to the need for further protection through other binding international and national legal mechanisms. They can also have an impact on the way national authorities, industry, researchers and others deal with genetic information and can in this way provide some form of protection.

I want to focus here on another type of human rights initiative and how it could be used in the Canadian context: the adoption of specific clauses in human rights law. An example of this approach is the Council of Europe’s *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*.<sup>192</sup> Although the legal impact of an international convention cannot be directly compared to internal constitutional or quasi-constitutional human rights provisions, the system of the European Human Rights Conventions has a significant impact on those states signing and ratifying a Convention. The Council of Europe’s *Convention for the Protection of Human Rights and Fundamental Freedoms* of 1950,<sup>193</sup> for example, and the case law developed by the European national courts and the European Court of Human Rights on the basis of the provisions of this convention, has had a profound impact on fundamental human rights in the member states of the European Council. Member states have been obliged to pay significant compensation and have frequently had to adapt their national laws following some of the decisions of the European Court of Human Rights. The fact that the Canadian Supreme Court has frequently referred to its decisions is indicative of its importance.

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<sup>190</sup> *Supra* note 186.

<sup>191</sup> *Supra* note 66 at 9.

<sup>192</sup> 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*, Eur. T.S. No. 164 (1997), online: Council of Europe, Treaty Office <<http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm>> [*Convention*]. For a comparison between U.S. statutes and the provisions in the European *Convention* dealing with genetics and for an interesting discussion of the potential impact of the *Convention* on insurance issues, see Anne Lawton, “Regulating Genetic Destiny: A Comparative Study of Legal Constraints in Europe and the United States” (1997) 11 *Emory Int. L. Rev.* 365.

<sup>193</sup> Council of Europe, *Convention for the Protection of Human Rights and Fundamental Freedoms*, Eur. T.S. No. 005 (1950), online: Council of Europe, Treaty Office <<http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm>>.

The *Convention on Human Rights and Biomedicine* entered into force on December 1, 1999, after it was ratified by 5 countries. As of August 2002, thirty-one states have signed it, of which thirteen have also ratified it.<sup>194</sup> Ratification involves formal approval of the *Convention* and integration of its provisions into national law, or adaptation of existing national laws to these provisions.<sup>195</sup>

The *Convention* contains both a specific prohibition on genetic discrimination and a “therapeutic” provision. Article 11 states that: “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.”<sup>196</sup> Article 12 of the *Convention* stipulates that genetic testing may be performed for health care purposes or for scientific research only and that appropriate genetic counselling should be provided. And while states can restrict rights and protective provisions of the *Convention* by law and when necessary “in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others,”<sup>197</sup> they cannot do so for articles 11 and 12.

The language of the *Explanatory Report* in its discussion of article 12 is also very clear that the aim of these provisions is to prevent genetic testing for other than health related reasons, even if people assent to it.<sup>198</sup> The *Explanatory Report* mentions that predictive testing for other than health related purposes entails a “disproportionate interference” with individual privacy rights. It further clearly rejects the right of insurers to make the conclusion or modification of an insurance contract dependent on genetic testing, because, to use the words of the *Report*, testing for such purposes constitutes “an illegal act.”<sup>199</sup> From other statements in the *Explanatory Report*, however, it appears the use of genetics as a means to indicate lower risk could still be acceptable and some form of fairness assessment could still be possible when determining whether a particular use of genetic information is acceptable.<sup>200</sup> It is yet to be seen what the impact of these provisions will be on insurance practice in Europe.

In insurance, the fairness of the distribution of private insurance goods should depend on the role they play and on the presence of other distributive mechanisms in society, such as appropriate welfare provisions and universal health care. It seems

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<sup>194</sup> For updated information, see the tables of signatures and ratifications for the *Convention* online: Council of Europe <<http://www.coe.fr/tablconv/164t.htm>>.

<sup>195</sup> Knoppers, Godard & Joly, *supra* note 66 at 12, mention that Georgia included the *Convention*'s restrictions into its internal legislation with a new law on patient rights.

<sup>196</sup> *Convention*, *supra* note 192, Art. 11.

<sup>197</sup> *Ibid.*, Art. 26(1).

<sup>198</sup> Council of Europe, *Explanatory Report to the 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), online: Council of Europe, Treaty Office <<http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm>> at para. 85 [*Explanatory Report*].

<sup>199</sup> *Ibid.* at para. 86

<sup>200</sup> For a more detailed discussion of the provisions of this *Convention*, see Lemmens, “Selective Justice”, *supra* note 5 at 358-360.

reasonable for an international convention to allow member states some flexibility in deciding how they want to implement a protective regime. Countries with an extensive welfare and social support system may be inclined to leave more freedom in the private insurance market, while others may seek more restrictions through the imposition of a higher ceiling for basic insurance contracts. But in those countries where there is guaranteed access to a “no-genetic-questions-asked” form of insurance, is it still important to have additional safeguards? Could a country that has such a policy, but no additional measures of protection against genetic discrimination, be held accountable for violation of the *Convention*?

This leads me to comment on the importance of guaranteeing human rights standards above and beyond access to basic insurance. Even if access to some basic level of insurance is ensured, concerns about genetic discrimination remain. Indeed, safeguarding access to some basic form of insurance without regard to genetic factors does not remove all concerns about the potential stigmatization and exclusionary treatment of people affected by a “disabling” genetic trait. Obviously, human rights can be violated even if basic needs are fulfilled. Comme-Chez-Soi cannot refuse to serve a meal to a coloured person on the grounds that there is a PizzaPizza next door, and the fact that there are Fiat Unos on the market cannot be invoked by a Ford Mustang dealer to justify his policy of only selling to men. Similarly, insurance contracts with “luxurious” coverage should not contain discriminatory provisions.

One could argue that the policy of offering access to basic insurance (ceiling approach) on the one hand and the human rights approach on the other hand deal with two different, though related, aspects of justice that are both recognized in Canadian human rights law. The ceiling approach is an ameliorative scheme, aimed at safeguarding access to an important socio-economic good that can be seen as an important component of participation in social life. Accordingly, Sandberg defines insurance contracts as “non-primary social goods.”<sup>201</sup> This type of legislation deals with providing the basis for goods required to lead a flourishing life, however, as I noted, human rights law is also concerned with such needs. In the context of insurance, it may be easier and more efficient to introduce access to basic insurance through a separate scheme such as a ceiling. Canadian human rights case law has focussed more upon the inherent dignity of individuals and the way it can be undermined by a lack of equal treatment. This is the more passive aspect of the human dignity notion. To address this issue, a human rights framework remains essential even if basic insurance is provided. Should provisions, similar to those in Europe, explicitly prohibiting genetic discrimination and only permitting genetic testing when it is performed for health care or research purposes, be introduced in Canadian human rights statutes?

The first question that one should ask is whether genetics-specific human rights clauses need to be introduced. I would like to make a distinction here between

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<sup>201</sup> *Supra* note 79 at 1554.

the social benefit of a firm public statement versus a legislative provision. Certainly, there are human rights concerns related to the use of genetic information that merit careful consideration and regulatory attention. The many international and national statements and reports on this issue strongly recognize this concern. More concretely, these international statements are timely declarations about the increased need for the protection of individuals affected by a genetic trait.

These declarations, however, are focussed on a specific concern, and this unfortunately sometimes leaves some with the impression that there are no other human rights issues related to the use of health information in general. In thinking about the implementation of protection in a legislative scheme, coherence and proportionality are important. In that respect, genetics cannot fundamentally be separated from other types of health information used for insurance purposes. Therefore, genetics-specific prohibitions in human rights statutes risk creating an unduly narrow focus and may themselves lead to unfair decisions.

There is also another concern. Susan Wolf, writing about the American genetic anti-discrimination statutes, argues these may contribute to what she calls “geneticism.”<sup>202</sup> According to Wolf, who invokes the lessons learned from racism and sexism, geneticism:

...is a long-standing and deeply entrenched system for disadvantaging some and advantaging others. It can be seen in the pervasive individual and institutional use of genetic information and concepts to disadvantage people whether singly or by creating groups. It predates any accurate understanding of genetics, and now refers to social structures, practices, beliefs, and predispositions that together support disadvantaging based on a mixture of accurate and inaccurate genetic ideas.<sup>203</sup>

In her view, genetics-specific legislation may contribute to this phenomenon in several ways. Referring to the need to protect people against genetic discrimination, she seems supportive of “the fiction that there is such a thing as a ‘normal’ genotype, and that the goal is to change the treatment of people who deviate.”<sup>204</sup> She rightly points out that a mere prohibition on the use of genetics for insurance purposes does not challenge the entire risk rating system of private health insurance systems, while giving the illusion that protection is in place. In a way, then, a specific prohibition on genetics may be seen as a confirmation of the legitimacy of unlimited underwriting based on other forms of health information. Genetics-specific protection may also leave untouched more important issues of systemic discrimination and could even lead to complete neglect of these issues.

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<sup>202</sup> Susan M. Wolf, “Beyond ‘Genetic Discrimination’: Toward the Broader Harm of Geneticism” (1995) 23 *J.L. Med. & Ethics* 345.

<sup>203</sup> *Ibid.* at 348 [footnote omitted].

<sup>204</sup> *Ibid.* [footnote omitted].

These concerns can be addressed to some extent by introducing a more inclusive provision in human rights legislation, which emphasizes the importance of protection against discrimination resulting from any type of health information. Wolf's points about systemic discrimination bring us to Canadian equality law. As I pointed out, the Supreme Court has, in recent cases, increasingly recognized the impact of discriminatory practices and the importance of removing barriers to access rather than just providing small-scale accommodation. The focus, in other words, should be on removing wider unjustified differential treatment, rather than singling out categories of health information which merit special protection. For these reasons, the Ontario Law Reform Commission's proposal to add a new, more general provision to the provincial human rights statutes seems a good solution. The Commission suggests a change be made to existing definitions of disability or handicap in human rights legislation to make sure future health risks and the perception of such risks are included in the definition of disability and covered under existing human rights law. It recommends the words "or for the reason that it is believed that the person will have" be added to the definition of disability.<sup>205</sup>

This proposal has two major advantages: it addresses the concerns about genetic discrimination in general by allowing courts to assess the impact of the use of "health information" in various social settings, including insurance and employment. It also avoids the pitfalls of a genetics-specific approach. An integration of this type of protective clause into human rights legislation also has a strong declaratory function. It affirms a societal commitment to protect those who are for genetic and other health-related purposes, more at risk of exclusion and discrimination in various walks of social life. More so than specific legislation focusing exclusively on insurance, it contributes to the affirmation of social values. Crafting protection in the language of human rights will probably create a different way of viewing genetic health differences. For that reason, even if it is possible to include genetic differences under the aegis of the notion of disability, it can be helpful to provide a specific clause. Although caselaw allows us to conclude that discrimination on the basis of genetic information would be protected through the prohibition against discrimination on the basis of disability, it would provide more certainty to add a general clause referring to future health risks. The only *caveat* I would like to express here is with respect to the integration of such change in connection with the definition of disability. It may be better, since less likely to be seen as a reflection of genetic determinism, to introduce a specific reference to future health risk, disconnected from the notion of disability.

Another option, which would not require legislative change, is to enact an interpretative guideline, adding into the existing terminology related to disability the notion of genetic risk status. The Ontario Human Rights Commission has recently declared that the notion of disability could be used to protect against

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<sup>205</sup> *Supra* note 165 at 231.

genetic discrimination.<sup>206</sup> The disadvantage of such approach, however, is that it seems to raise precisely the concerns voiced by Wolf, i.e., that it could be seen as an institutionalized confirmation of the fact that a certain genetic risk status is a disadvantage. This is not to say that, in the absence of a legislative change, the disability clause, could not be invoked by the courts to protect against genetic discrimination. However, there may be a difference between allowing the courts to offer protection through the disability clause, and making an official interpretative declaration that a certain genetic risk status is to be equated with disability.

## Conclusion

In this paper, I have discussed various ways in which different countries and organizations have attempted to address concerns raised by the potential use of genetics for insurance purposes. Many of these options merit a more substantial assessment. It is, however, telling that apparently none of these options has so far been seriously and openly debated by provincial and federal governments in Canada. Although various commentators, including law commission reports and other committee reports mentioned in this article, have argued for the need of better protection against genetic discrimination, no significant legislative or regulatory initiatives have emerged. In contrast with many other countries, even the industry itself has not felt the need to reassure the public by implementing a moratorium, or by suggesting it would limit its use of genetic information awaiting a fuller democratic debate. In this paper, I have suggested a combination of various options should be considered. Changes to insurance law and human rights law should be combined with other measures.

Protective measures focussing on insurance law should also be combined with an overall, more systematic approach to deal with the implications of the increased predictive accuracy of health information and the potential abuse of that information outside the health care context. The Legal and Ethical Subcommittee of the Ontario Governmental Committee on New Predictive Genetic Information is about to release its report in which it calls for a clear regulatory approval system of genetic testing, akin to the existing drug approval system. It recommends genetic testing should be submitted to a systematic review of its value and validity; and specialized review committees should also determine in what context specific forms of testing could be used. Such a review system should provide pre-emptive protection and should avoid a situation whereby insurance applicants, employees, immigrants, and others, who have been discriminated against on the basis of genetics, have to enter court proceedings to remedy the violation of their rights. While court-based remedies should obviously remain available, it would be much more appropriate in this context to avoid inappropriate use of genetics in the first place by establishing a regulatory review system for genetic testing. Although the regulatory review of new drugs and medical devices is itself in need of improve-

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<sup>206</sup> Canadian Human Rights Act Review Panel, *Promoting Equality: A New Vision* (Ottawa: Canadian Human Rights Act Review Panel, 2001) at 101, Recommendation 119.

ment, a regulatory-based review of genetic testing can be defended on similar policy grounds. Preliminary review should enable us to determine what form of genetic testing can be scientifically validated and socially justified, for what purpose it can be used, and who can conduct this form of testing.

This regulatory system should be statutorily anchored and receive a general mandate. The social implications of genetic testing far exceed the insurance context. An adequate review system should be developed to counter potential inappropriate use of genetic testing in various other contexts, such as employment, immigration, education, and sports.

Considering the wider societal and human rights implications of genetic testing, it is crucial the review agency is developed independent from industry, adequately represents the public interest, and takes into consideration the human rights implications of genetic testing. As I pointed out earlier,<sup>207</sup> some provincial human rights codes provide human rights commissions with the power to determine what constitutes a *bona fide* distinction for insurance purposes.<sup>208</sup> It is also worth pointing out that the guidelines developed by the Supreme Court in its recent *Meiorin* and *Grismer* cases provide useful benchmarks for decision making by these review committees.

Whatever model for review is chosen, we should keep in mind the solid criticism of Justice McLachlin (as she then was) in the *Zurich* case, directed towards the majority's reliance on a regulatory body whose mandate it is to ensure the orderly administration of the insurance industry. She noted the risk of regulatory capture in conferring broad powers to a regulatory body that must work closely with the industry it is regulating:

This tendency of regulators of an industry to see the world through the eyes of that industry, sometimes referred to as "industry capture", is understandable and in some respects may be beneficial. But it provides good reason for the legislature's placing the determination of human rights violations not in the hands of industry regulators, but in the hands of a separate body.<sup>209</sup>

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<sup>207</sup> See Lemmens, "Selective Justice", *supra* note 5 at 410. For a more detailed discussion of regulatory review models, see *ibid.* at 407-412.

<sup>208</sup> See e.g. *Human Rights Code*, R.S.N.L. 1990, c. H-14, s.6(2); *Human Rights Act*, R.S.P.E.I. 1988, c. H-12, s. 33(2)(b); *Human Rights Act*, R.S.N.S. 1989, c. 214, s. 15(2).

<sup>209</sup> *Supra* note 52 at 388.