



# Genetics and Life Insurance : A Comparative Analysis

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## Abstract

The debate surrounding the role of life insurance, the necessity of risk rating, and the notion of “acceptable discrimination” has raised questions about the larger social role of insurance. Recent developments in the field of genetics, allowing insurers to make use of genetic testing technology as a new underwriting tool, have reinvigorated this debate.

This article presents a comparative study of positions taken in countries on issues in genetics and life insurance. We will analyze the 43 selected countries and comment on their potential for ensuring a more equitable access for life insurance applicants.

## Introduction

Life insurance is a private contract between the policyholder and the insurer. It is designed to provide financial protection to beneficiaries, in the event of the death of the insured. To calculate the amount of the premium, insurers use information such as : age, sex, health status and lifestyle factors as well as some information on the applicant’s familial health history. The insured will then be assigned to a group comprised of people with similar risk factors. By its very nature then, the process of underwriting discriminates between individuals on the basis of individual and familial characteristics.<sup>i</sup>

This “discriminatory” component of the insurance contract is at the center of the dilemma. Insurers currently have the possibility of using genetic information for insurance underwriting. While insurers invoke the “mutuality” principle underlying the private life insurance contract as well as the risks of “antiselection”<sup>ii</sup> to justify their access to genetic information,<sup>iii</sup> patients’ groups and human rights activists invoke the risk of discrimination and the social role of life insurance.<sup>iv</sup> The familial and sensitive nature of genetic information also serves to exacerbate the debate.

Only a limited number of predictive genetic tests are sufficiently reliable to be of real use to the insurers.<sup>v</sup> Yet, a large number of insurers feel that it is necessary to have access to all health information (including genetic information) pertaining to insurance

applicants or to other people whose lives are to be insured. This would include genetic information that has become available in both the clinical setting and in the context of genetic research. The demand for access to genetic information is particularly worrisome for participants in genetic research. This may very well have a negative impact on genetic and genomic research, and result in preventing a given population from benefiting from advances.<sup>vi</sup>

Many industrialized countries have attempted to ensure the equitable integration of genetics in the underwriting process. Others go so far as to use legislation to prohibit by access insurers to genetic information. Having conducted an international comparative study of the positions of 43 countries,<sup>vii</sup> we distinguish the emergence of seven positions: human rights, therapeutic limit, legislative prohibition, quality control system, moratorium, proportional approach, and, the *status quo*.

The present article will give a short description of these various positions as well as an evaluation of their potential.

## Human Rights

In its 1997 *Universal Declaration on the Human Genome and Human Rights*, UNESCO proclaims that:

“No 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 human dignity.”<sup>viii</sup>

This approach, which aims to prohibit discrimination based on the genetic characteristics of the individual, is also found in several international guidelines<sup>ix</sup>. Although guidelines are not legally binding instruments, in time they have considerable influence on policymakers creating pressure on national governments to adapt their legislative or regulatory regimes, where needed. The *Universal Declaration on the Human Genome and Human Rights*, for example, serves as a pivotal instrument for policymaking on genetics and has inspired several laws and professional norms<sup>x</sup>.

In Europe, according to the *Convention on Human Rights and Biomedicine* : “Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited<sup>xi</sup>.” Unlike the *Declaration on the Human Genome and Human Rights*, the *Convention on Human Rights and Biomedicine* is a legally binding instrument in the European countries that have ratified it. Ratification procedures differ in each country, but normally involve parliamentary approval. Prior to ratification, each state has to bring its laws into line with the *Convention*. This may require a change or not, or, a new law. Such legislation must include legal sanctions and require compensation for individuals who have suffered undue harm following medical treatment or research<sup>xii</sup>.

Some countries seem reluctant to introduce specific protection against genetic discrimination in human rights legislation. One reason may be that they see no need for such a genetic-specific approach; or, they are concerned about the consequences of adding another ground of discrimination to existing legal, often constitutional documents. It should be noted, however, that a prohibition against genetic discrimination does not necessarily mean that all forms of differential treatment based on genetic information become impossible. As is the case when other “grounds of discrimination” are mentioned in human rights document, further interpretation is needed. The UNESCO *Declaration*, for example, captures it well. The aim of anti-discrimination provisions is to prohibit discrimination that impacts on human rights, fundamental freedoms and human dignity.

Others have expressed concern that distinguishing genetic information from other grounds of disability in human rights legislation (or elsewhere) could reinforce genetic determinism: the belief that carrying a specific genetic mutation has a much more determinant and inevitable impact on people’s health, well-being and potentially even behaviour, than other health factors. This could contribute to stigmatization and discrimination, and thus have the contrary effect.

The tendency to single out genetics for special protection has been referred to as ‘genetic exceptionalism.’<sup>xiii</sup> This concern about ‘genetic exceptionalism’ is particularly poignant in the United States, where most states have introduced some protection against genetic discrimination in the context of health insurance. It has been argued that this focused protection against genetic discrimination is unfair since so many people remain excluded from health insurance on other grounds. Although the consequences are less severe when it comes to life insurance, it can also be argued that prohibiting the use of genetics in insurance underwriting while allowing similar non-genetic risk factors to be used is unfair.<sup>xiv</sup>

Some have argued also that the term ‘discrimination’ in the context of insurance can cause confusion and that the legislator should specify if she wishes to prohibit all types of genetic discrimination, including actuarial or rational discrimination, or simply irrational discrimination.<sup>xv</sup>

Another approach to ensure protection against genetic discrimination, while avoiding genetic exceptionalism, is to adapt existing human rights codes so that they clearly include genetic susceptibility as one among many other prohibited grounds of discrimination. The Ontario Law Reform Commission recommended, for example, that the Ontario Human Rights Commission should issue an interpretive rule that states that genetic conditions are covered under the existing human rights protections.<sup>xvi</sup> And it recommended that the existing definition of “handicap” should be changed to include the following: “‘because of handicap’ means for the reason that the person has or has had, or is believed to have or have had, *or for the reason that it is believed that the person will have a disability.*”<sup>xvii</sup> A recent report prepared for the Ontario Advisory Committee on Genetics reiterates this recommendation.<sup>xviii</sup> Being regarded or perceived as having a “genetic” disability would thus be prohibited.

The advantage of this approach is that it indicates that genetic susceptibility or predisposition is not necessarily different from other forms of discrimination based on the perception of the power of predictive health information while it also affirms the need to protect people against inappropriate use of health information by third parties.

## Therapeutic Model

This model, especially popular in European countries, is used in the *Convention on Humans Rights and Biomedicine* of the Council of Europe. According to the Convention (Art. 12) (S.12):

“Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling..”

This Convention, effective since 2000, has been ratified by 17 members of the Council of Europe including a strong proportion of Eastern-European countries.<sup>xix</sup> The major problem with the therapeutic model is that it does not protect information on a person who has already undergone a genetic test that is recorded in the medical file.<sup>xx</sup> This explains why the *Convention on Humans Rights and Biomedicine* uses the therapeutic model in conjunction with the human rights approach. It prohibits discrimination against a person based on his or her “genetic inheritance” and at the same time limits the uses of predictive genetic tests to health or research purposes exclusively. However limited, the therapeutic model remains adequate in preventing insurers from imposing genetic testing on insurance candidate.

## Legislative prohibition

Another solution found among the European countries of civil law tradition<sup>xxi</sup> is the insertion of a provision simply prohibiting insurers from asking questions relating to either genetic test results or other genetic information. At first glance, this approach could offer adequate protection to genetic information obtained in the clinical or research contexts. However, in addition to being a relatively inflexible solution, likely to reinforce the tendency to genetic exceptionalism,<sup>xxii</sup> this model also demonstrates the difficulty of adequately defining what constitutes a genetic test or genetic information.<sup>xxiii</sup> The consequences of this problem are prohibitions which are too broad,<sup>xxiv</sup> too restricted,<sup>xxv</sup> or have an uncertain reach.<sup>xxvi</sup>

The legislative prohibition model is also problematic since it does not take into account the “antiselection” phenomenon. While “antiselection” has not been proven in recent studies of consumer behaviors,<sup>xxvii</sup> the potential risk for “antiselection” remains.

Despite the difficulties it presents, a legislative intrusion in the private insurance market could be justified because the product of insurance is inextricably linked to the acquisition of social goods (i.e. houses, cars, loans etc.) in modern society.<sup>xxviii</sup>

## **System of regulatory review of the use of genetic tests**

After a two year study of an unprecedented scope on the protection of genetic information in Australia, the *Australian Law Reform Commission* concluded that the Australian public doubted the capacities of insurers to interpret and use genetic information in a scientific manner for the underwriting process. Consequently, the Commission recommended that the *Human Genetics Commission of Australia* (HGSA) exert an independent control on the use of predictive genetic tests for insurance. Thus, if implemented, the HGSA will have to rule on the scientific reliability and the actuarial relevance of predictive genetic tests. This new system, inspired by recent British developments,<sup>xxix</sup> avoids the worst abuses, while leaving a considerable margin to the insurers who would like to use certain genetic tests in the underwriting process. However, because this system does not prevent genetic discrimination supported by actuarial data, is it sufficient to alleviate the public's anxiety concerning genetic progress?

A more interventionist approach is to empower a governmental regulatory body to determine more than just the actuarial reliability of the use of a test. A regulatory review structure exists already for medical devices and drugs. The same should exist for genetic testing, although the review system should do more than simply determining the validity of a new test. A regulatory agency should also review the potential social impact of allowing the use of certain forms of genetic testing and should determine its value, as well as the context in which these tests could be used. Under this system of review, the approval of a genetic test should include details about who can conduct an approved test and for what purposes. This is what a recent Ontario report also recommends.<sup>xxx</sup>

## **Moratorium**

A particularly popular approach, often used in countries of the common law tradition, is the adoption of a voluntary moratorium by insurers. A moratorium can be defined as a voluntary agreement by a group of insurers (often through an official representative organization), neither to request genetic testing of insurance applicants<sup>xxxii</sup> nor to use genetic test results.<sup>xxxii</sup> Moratoria are often adopted by insurers as a response to public or even governmental pressure.<sup>xxxiii</sup>

The major interest of a moratorium is its flexibility and its ease of implementation. Insurers are free to limit their engagement (i.e. temporal limits, financial limits, definitional limits, etc.) in the way which they feel to be most suitable. The majority of moratoria are limited in time, the insurers giving themselves a certain period to evaluate the actuarial relevance of genetic tests. Moratoria can be particularly useful as a temporary measure to

reassure the public and to exercise pressure on competitors within the industry to accept a common standard.

Although not avoiding the definitional problems associated with certain approaches discussed previously, the flexibility of a moratorium makes it a particularly attractive system to deal with an issue (on a temporary basis) which is affected by technological developments and where governments or regulators are in doubt about the appropriate regulatory structure.

One of the significant limitations of this approach is that it relies on the goodwill of those signing on to the moratorium. Professional associations that establish a moratorium may have moral persuasion over their members but they do not have real power over those in the industry who do not feel bound by its rules.<sup>xxxiv</sup> This hurdle can be avoided by involving the government in the process in order to ensure the respect of a moratorium and thus increase its credibility.<sup>xxxv</sup>

## **Proportional Approach**

The proportional approach is generally used in conjunction with a moratorium or a legislative prohibition.<sup>xxxvi</sup> This approach allows insurance applicants to abstain from revealing their genetic test results when the cost for a desired policy is below a certain established amount. At times, this approach is extended to cover other types of information usually required by the insurers. The proportional approach guarantees the applicant access to a minimum amount of life insurance without having to reveal any health information. Unfortunately, this latest type of insurance product either provides coverage for a very low amount, or is very expensive. Due to cost, this form of insurance is unpopular among people who do not present a particularly high risk.

An interesting (and perhaps more equitable) variation of the proportional approach, consists of allowing questions about genetic tests result only when the amount of life insurance subscribed exceeds the annual income of the insurance candidate.

## **Status Quo**

The limited number of genetic tests that are both available on the market and useful for insurers<sup>xxxvii</sup>, together with the paucity of legally reported cases of arbitrary genetic discrimination<sup>xxxviii</sup>, have persuaded certain governments<sup>xxxix</sup> to wait before taking any specific measures to prohibit access by insurers to genetic information. According to supporters of the “status quo”, the protection granted to the population through human rights and privacy laws are enough to provide an adequate safeguard against unwarranted discrimination. Furthermore, the competitive forces of the market will constitute additional protection against possible abuses by insurers.<sup>xl</sup>

Notwithstanding the fact that existing legal mechanisms often provide some protection, the decision to maintain the “status quo” does not take into consideration public perception as well as its impact on human genetic research. Studies have shown that the public’s fear for “genetic discrimination” by insurers lies behind reluctance to participate in research or a decision to withdraw.<sup>xli</sup> Such fear could also prevent some from undergoing genetic tests for health care purposes.<sup>xlii</sup>

The “status quo” also does not provide satisfactory answers to the wider debate on whether there should be limits to the right of insurers to use information on family history. The value of providing some form of guaranteed insurance to the population at large is also incompatible with this approach.

## **Conclusion**

Because the private life insurance market requires the classification of applicants within different risk levels, it necessarily involves a degree of discrimination<sup>xliii</sup>. Very few genetic tests offer sufficient reliability to be of use to insurers. Even in the few cases where genetic tests could currently be considered reliable enough to be of interest to insurers, their use for insurance underwriting remains controversial.<sup>xliv</sup> A growing number of industrialized countries have become conscious of the importance of having access to a minimum level of life insurance. The interest of insurers in knowing genetic test results is therefore perceived by many as a threat to a social or quasi-social good.

Several countries have attempted to restrict access by insurers to genetic information. Conversely, others have taken a wait-and-see approach, hoping that traditional human rights legal instruments along with the competitive forces of the market would be sufficient to prevent an unwarranted use of genetic information.

It is important to understand not only the uncertainty associated with genetic data, but also the socio-political and economical strengths of insurers and the potential social implications of the use of genetic information. The adoption of a voluntary moratorium by associations of insurers has the advantage of providing a high level of flexibility while reassuring the population. At a minimum, the publication of a Code of Conduct by insurers would add transparency to the process and inform the population. A moratorium would create a space for further debate about the appropriate regulatory and/or legislative interventions required to deal with the social implications of the use of genetic and other forms of health information outside of the health care context. In the case of incapacity to enforce the respect of a moratorium by insurers, legislative intervention might prove necessary. Any intervention in this area however, should be accompanied by a wider public debate about the social role of life insurance and about the importance and limitations of the current underwriting process.

## Restrictions to the Use of Genetic Information by Insurers for Life Insurance Underwriting\*

\*This table is an updated version of the original table from B. M. KNOPPERS, B. GODARD, Y. JOLY, "Life Insurance and Genetics: A Comparative International Overview" in ROTHSTEIN M. (ed.) Life Insurance: Medical Underwriting and Social Policy, Cumberland, MIT Press (in press).

	MORATORIUM	LEGISLATION	GUIDELINES	OTHER	DRAFT
AUSTRIA	No	Yes	No		
AUSTRALIA	Partial Exp : 2005	No	Yes	A bill on genetic privacy was introduced in 1998 but has not yet been accepted.	A joint inquiry on the protection of genetic information has recently been conducted by the Australian Law Reform Commission.
BELGIUM	No	Yes	No		
BULGARIA	No	No	No	Ratified the Oviedo convention 01/08/03.	A constitutional amendment prohibiting genetic discrimination has been introduced in the National Assembly (summer 2002).
CANADA	Partial	No	Yes		
CHILE	No	No	Yes		
CYPRUS	No	No	No	Ratified the Oviedo convention 01/07/02.	
CZECH REPUBLIC	No	No	No	Ratified the Oviedo convention 01/10/01.	
CROATIA	No	No	No	Ratified the Oviedo convention 28/11/03.	
DENMARK	No	Yes	Yes	Ratified the Oviedo convention 01/12/99.	
ESTONIA	No	Yes	No	Ratified the Oviedo convention 01/06/02.	



	MORATORIUM	LEGISLATION	GUIDELINES	OTHER	DRAFT
FINLAND	Yes Unlimited amount Exp: none	No	Yes		
FRANCE	Yes Unlimited amount Exp: 2004	Yes	Yes		
GERMANY	Yes Limited amount Exp: 2006	No	Yes		A parliamentary commission has declared that insurers should not use genetic test results.
GEORGIA	No	Yes	No	Ratified the Oviedo convention 01/03/01.	
GREECE	Partial	No	Yes	Ratified the Oviedo convention 01/12/99.	
HUNGARY	No	No	Yes	Ratified the Oviedo convention 01/05/02.	
ICELAND	No	No	No	A bill has been presented but has not been enacted.	
INDIA	No	No	Yes		
IRELAND	Yes Limited amount Some conditions are excluded Exp:2005	No	No		
ISRAËL	No	Yes	No		
ITALY	No	No	Yes		Guidelines for genetic testing to be adopted shortly by the ministry of health.

	MORATORIUM	LEGISLATION	GUIDELINES	OTHER	DRAFT
JAPAN	No	No	Yes		<p>The Association of Life insurance Medicine of Japan has a code of practice in preparation.</p> <p>Ministry of health to issue guidelines.</p> <p>Insurers are not allowed to ask for family history information.</p>
LITHUANIA	No	No	No	Ratified the Oviedo convention 17/10/02.	
LUXEMBOURG	No	Yes	Yes		
MOLDOVA	No	No	No	Ratified the Oviedo convention 26/11/02.	
NETHERLAND	No	Yes	Yes		
NEW ZEALAND	Partial	No	Yes		
NORWAY	No	Yes	Yes		
PORTUGAL	No	No	Yes	Ratified the Oviedo convention 13/08/01. Article 13 of the Portuguese Constitution could prevent insurers to discriminate on the basis of genetic test results.	A task force established by the ministry of health has prepared key guidelines addressing genetic testing.
ROMANIA	No	No	No	Ratified the Oviedo convention 01/08/01	
SAN MARINO	No	No	No	Ratified the Oviedo convention 01/12/99.	
SINGAPORE	No	No	Yes		
SLOVAKIA	No	Yes	No	Ratified the Oviedo convention 01/12/99.	

	MORATORIUM	LEGISLATION	GUIDELINES	OTHER	DRAFT
SLOVENIA	No	No	No	Ratified the Oviedo convention 01/12/99.	A Bill is expected to be drawn up in the near future addressing human genetics.
SOUTH AFRICA	Partial	No	Yes		Insurers are not allowed to ask for family history information.
SOUTH KOREA	No	No	No		A Bill prohibiting discrimination in insurance and employment has passed through the national assembly, presidential sanction is planned for February 2005.
SPAIN	No	No	No	Ratified the Oviedo convention 01/01/00. The Spanish constitution could prevent insurers to discriminate on the basis of genetic test results.	Under current law insurers do not have an <i>ex lege</i> right entitling them to gather genetic information concerning a potential applicant.
SWEDEN	Yes Limited amount Exp: Dec 2004	Yes	Yes		
SWITZERLAND	Yes	Yes	Yes		
TAIWAN	No	No	No		Insurers are not allowed to ask for family history information.
TURKEY	Yes <sup>(1)</sup>	No	No		
UNITED KINGDOM	Yes Limited amount Some conditions are excluded Exp: 2006	No	Yes		
UNITED STATES (federal government)	No	No	No		Several bills addressing genetics and insurance have been drafted, but none enacted.

## Moratorium

(also includes voluntary agreements between governments and insurers)

Partial: Insurers will not ask applicants to undergo genetic testing but may request the results of genetic tests already taken.

Limited amount: Insurers will not ask applicants to undergo genetic testing or request the results of genetic tests already taken unless the insurance policies asked for are over a given amount.

Unlimited amount: Insurers will never ask applicants to undergo genetic testing or request the results of past genetic tests.

## Legislation

Covers genetic specific legislation, prohibiting genetic testing at large, or insurers access to genetic tests.

## Guidelines

Covers any guidelines made by scientific or professional organizations on the subject of genetics and insurance.

## Convention on Human Rights and Biomedicine

States that have ratified this Convention are bound by it. The Convention forbids any kind of discrimination against a person based on genetic heritage. Genetic testing should only be permitted for health or research purposes.

(1) Additional informations on the moratorium were unavailable.

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<sup>i</sup> C.D. DAYKINS, D. A. AKERS, A. S. MACDONALD, T. MCGLEENAN, D. PAUL, P.J. TURVEY, “Genetics and Insurance - Some Social Policy Issues” (2003) 9: 4 *British Actuarial Journal* 793.

<sup>ii</sup> Since false or missing information on a person can lead to an assessment of risk that is not actuarially sound affecting the premium and skewing the insurance pool. Insurers fear that following a positive genetic test result, people will try to buy large policies at a favorable premium based on genetic information that is not shared with the insurer and that it will create an asymmetry of information. This behavior if it becomes widespread could lead to a substantial loss in revenue for the insurance companies and eventually to the collapse of the mutuality based private insurance system.

<sup>iii</sup> A. A. DICKE, “Perception Vs. Reality – Life Insurance and Genetic Testing” (2002) November/December, *Contingencies*, 34. A. and A. READ “Genetics and Insurance” (2002) 2:5 *Genetics Law Monitor* 4.

<sup>iv</sup> INTERNATIONAL HUNTINGTON ASSOCIATION, *Guidelines for the Molecular Genetics Predictive Test in Huntington's Disease*, Netherlands, (1994), HEREDITARY BREAST CANCER SOCIETY OF ALBERTA, *Letter to the Honourable Anne McLellan* (2002) on line : <http://www.cbcn.ca/english/advocacy.php?show&70>, and T. LEMMENS, “Selective Justice, Genetic Discrimination, and Insurance : Should We Single Out Genes in Our Laws ?” (2000) 45 *McGill L.J.* 389-399.

<sup>v</sup> MUNICH RE GROUP, *Genetic Testing and Insurance – A Global View*, Munchener Ruckversicherungs-Gesellschaft, Munchen, (2000) 6-10.

<sup>vi</sup> B. M. KNOPPERS & al., “Genetics and Life Insurance in Canada : Points to Consider” (2004) 170:9 *CMAJ* on line : [www.cmaj.ca](http://www.cmaj.ca) .

<sup>vii</sup> Austria, Australia, Belgium, Bulgaria, Canada, Chili, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, India, Ireland, Israel, Italy, Japan, Luxembourg, Moldavia, Netherlands, New Zealand, Norway, Portugal, Rumania, Russia, South Korea, Spain, San-Marino, Singapore, Slovakia, Slovenia, South Africa, Sweden, Switzerland, Turkey, United Kingdom, United States.

<sup>viii</sup> UNESCO – INTERNATIONAL BIOETHICS COMMITTEE (IBC), *Universal Declaration on the Human Genome and Human Rights*, Paris, (1997) s. 6.

<sup>ix</sup> See for example : ECONOMIC AND SOCIAL COUNCIL OF THE UNITED NATIONS, *Argentina Resolution Genetic Privacy and Non-Discrimination*, Geneva (2001), res. 3. INTERNATIONAL BAR ASSOCIATION, *Draft International Convention on the Human Genome*, London (1996) art. 5. INTERNATIONAL HUNTINGTON ASSOCIATION, *loc. cit.*, note 4, rec. 2.3. WORLD HEALTH ORGANIZATION (WHO), *Human Genetics and Noncommunicable Diseases*, Geneva (1999) WORLD HEALTH ORGANIZATION (WHO), *Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services*, Geneva (1997).

<sup>x</sup> Y. JOLY, « Accès aux médicaments : le système international des brevets empêchera-t-il les pays du tiers monde de bénéficier des avantages de la pharmacogénomique » 16:1 *Les cahiers de la propriété intellectuelle* (2003) 153.

<sup>xi</sup> COUNCIL OF EUROPE (CE) *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*, Oviedo, (1997), art 11.

<sup>xii</sup> B. M. KNOPPERS, B. GODARD, Y. JOLY, “Life Insurance and Genetics: A Comparative International Overview” in ROTHSTEIN M. (ed.) *Life Insurance: Medical Underwriting and Social Policy*, Cumberland, MIT Press (in press).

<sup>xiii</sup> T.H. MURRAY, “Genetic Exceptionalism and ‘Future Diaries’. Is Genetic Information Different from Other Medical Information?” in M.A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, New Haven, Yale University Press, 1997, p. 68.

<sup>xiv</sup> See the discussion of this issue and other references in T. LEMMENS, *loc. cit.*, note 4, 369-376.

<sup>xv</sup> By the use of the terms arbitrary or irrational genetic discrimination, authors are referring to situations where insurance candidates have been refused life insurance or have been subjected to higher premiums without having the decision supported by the level of risk., Cf. M. ROTHSTEIN, M. R. ANDERLIK, “What is Genetic Discrimination, and When and How Can it be Prevented ?” 3:5 *Genetics IN Medicine* 354-358.

<sup>xvi</sup> ONTARIO LAW REFORM COMMISSION, *Report on Genetic Testing*, Toronto (1996) 145-146.

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- <sup>xvii</sup> *Id. rec.* 18 [emphasis added].
- <sup>xviii</sup> T. LEMMENS, M. LACROIX, R. MYKITIUK, eds., *Reading the Future? -- Legal and Ethical Challenges of New Predictive Genetic Testing* (submitted for publication).
- <sup>xix</sup> Bulgaria, Cyprus, Czech Republic, Croatia, Denmark, Spain, Estonia, Georgia, Greece, Hungary, Lithuania, Moldavia, Portugal, Romania, St. Marin, Slovakia, Slovenia.
- <sup>xx</sup> B. M. KNOPPERS, B. GODARD, Y. JOLY, *loc. cit.*, note 12.
- <sup>xxi</sup> Austria, Belgium, Denmark, Estonia, France, Georgia, Luxembourg, Netherlands, Norway, Slovakia, Sweden, Switzerland.
- <sup>xxii</sup> P. KOSSEIM, M. LETENDRE, B. KNOPPERS, "Protecting Genetic Information: A Comparison of Normative Approaches" (2003) 2 *GenEdit* 1-6.
- <sup>xxiii</sup> Y. JOLY, B. M. KNOPPERS, B. GODARD, "Genetic Information and Life Insurance a 'Real' Risk?" (2003) 11 *European Journal of Human Genetics* 562.
- <sup>xxiv</sup> DENMARK, *Danish Insurance Contracts Act (1997)* Insurance companies may not : "request, obtain or receive and use information that may shed light on a person's genetic make-up and the risk of developing or contracting diseases, which includes demanding examinations necessary to generate such information."
- <sup>xxv</sup> AUSTRIA, *Federal Law Of 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, (and Amending the Product Liability Law)*, art. 67 : "It shall be prohibited for employers and insurance companies, including their representatives and associates, to collect, request, or accept the results of genetic testing from their employees, persons, or insurance personnel , or to utilize such data in any other way."
- <sup>xxvi</sup> FRANCE, *LAW No 2002-303 of March 4, 2002 relating to the rights of the patients and the quality of the system of health* (1) art. 98 : « Les entreprises et organismes qui proposent une garantie des risques d'invalidité ou de décès ne doivent pas tenir compte des résultats de l'examen des caractéristiques génétiques d'une personne demandant à bénéficier de cette garantie, même si ceux-ci leur sont transmis par la personne concernée ou avec son accord. En outre, ils ne peuvent poser aucune question relative aux tests génétiques et à leurs résultats, ni demander à une personne de se soumettre à des tests génétiques avant que ne soit conclu le contrat et pendant toute la durée de celui-ci. »
- <sup>xxvii</sup> K. AKTAN - COLLAN, A. HAUKKALA, H. KÄÄRIÄINEN, "Life and Health Insurance Behaviour of Individuals Having Undergone a Predictive Genetic Testing Programme for Hereditary Non-Polyposis Colorectal Cancer" (2001) 4 *Community Genet* 219-224., C.D. ZICK, K. R. SMITH, R.N. MAYER, J. R. BOTKIN, "Genetic Testing, Adverse Selection , and the Demand for Life Insurance" (2000) 93 *Am. J. Med. Genet.* 29-39.
- <sup>xxviii</sup> T. MCGLEENAN, "Legal and Policy Issues in Genetics and Insurance" (2000) 3 *Community Genet* 49., T. LEMMENS, *loc. cit.*, note 4, 389-99.
- <sup>xxix</sup> Cf. HUMAN GENETICS ADVISORY COMMISSION (HGAC), *The Implications of Genetic Testing for Insurance*, London, (1997).
- <sup>xxx</sup> T. LEMMENS, M. LACROIX, R. MYKITIUK, eds., *op. cit.*, note 18.
- <sup>xxxi</sup> South Africa, Australia, Canada, Greece, New Zealand.
- <sup>xxxii</sup> Germany, Ireland, Finland, Sweden, United Kingdom.
- <sup>xxxiii</sup> T. LEMMENS, "Genetics and Insurance Discrimination : Comparative Legislative, Regulatory and Policy Developments and Canadian Options" 2003 Special Edition *HLJ* p.56-64.
- <sup>xxxiv</sup> *Id.*, 63.
- <sup>xxxv</sup> Cf. UNITED KINGDOM GOVERNMENT DEPARTMENT OF HEALTH, *Government Response to the Report from the House of Commons Science and Technology Committee : Genetics and Insurance* (2001).
- <sup>xxxvi</sup> ASSOCIATION OF BRITISH INSURERS (ABI), *Genetic Testing - ABI Code of Practice*, United Kingdom, (1999)., THE NETHERLANDS, *Medical Examinations Act* (1998).
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- <sup>xxxviii</sup> D. C. WERTZ, "Genetic Discrimination : Results of a Survey of Genetics Professionals, Primary Care Physicians, Patients and the Public" (1999) 7:3 *Health Law Review* 7-8., K. BARLOW-STEWART, D. KEAYS, "Genetic Discrimination in Australia" (2001) 8 *Journal of Law and Medicine* 250-262.
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- <sup>xl</sup> W. NOWLAN, "A Rational View of Insurance and Genetic Discrimination" (2002) 297 *Science* 195-197., A. READ, *loc. cit.*, note 3, 7.

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