

CAN INSURANCE LAW ACCOMMODATE THE UNCERTAINTY ASSOCIATED WITH PRELIMINARY GENETIC INFORMATION?

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This paper discusses how the results of genetic testing could be used in the context of life insurance contracts. It highlights how current insurance law offers some protection against inappropriate use of genetic information. On the basis of an analysis of the case law, the argument is made that Canadian insurance law does leave room for policy considerations and that the courts' decisions often reflect concerns for fairness which differ from the actuarial fairness concept supported by insurance companies. The paper also recommends changes to insurance law to prevent inappropriate use of genetic and other health information.

Cet article décrit la manière dont les résultats de tests génétiques pourraient être utilisés dans le cadre de contrats d'assurance-vie. Il explique de quelle façon le droit des assurances actuel offre une certaine protection contre l'emploi inapproprié de données génétiques. D'après une analyse de la jurisprudence, le droit canadien des assurances permettrait de tenir compte de considérations de principe et les décisions des tribunaux traduiraient souvent des soucis d'équité qui diffèrent du concept d'équité actuarielle appuyé par les assureurs. Le document recommande également de modifier le droit des assurances pour empêcher l'emploi inapproprié de renseignements génétiques et d'autres renseignements sur la santé.

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I. <i>Introduction</i>	358
II. <i>New Genetic Developments and Insurance</i>	360
III. <i>What is Genetic Testing?</i>	364
IV. <i>Framing the Debate: What is a Life Insurance Contract?</i>	367
V. <i>Underwriting and Life Insurance</i>	371
A. <i>What is Insurance Underwriting?</i>	371
B. <i>Sources of Underwriting</i>	374
1. <i>Insurance Applicants' Declarations</i>	374
2. <i>Medical Files</i>	374
3. <i>The Medical Information Bureau</i>	377
4. <i>Medical Testing</i>	378
VI. <i>The Concept of Utmost Good Faith</i>	379
VII. <i>What are the Reasons for Using Genetic Information and Genetic Testing for Insurance Purposes and what are the Concerns?</i>	382
A. <i>Adverse Selection</i>	382
B. <i>Actuarial Fairness</i>	387
VIII. <i>Canadian Insurance Law and Genetic Testing</i>	392
A. <i>Duty of Disclosure: General Principles</i>	393
1. <i>Facts that are Material to the Risk</i>	396
2. <i>Facts Known to the Applicants</i>	398
B. <i>Sanction for Failure to Respect the Duty of Disclosure</i>	404
C. <i>The Incontestability Period</i>	405
IX: <i>Conclusion - Genetic Information in Insurance Law: Current Mechanisms, Future Options</i>	406

I. Introduction

When Mr. Tremblay died in a car accident at the end of the 1980s, his spouse asked their insurance company, L'Industrielle-Alliance, to pay out his life insurance coverage. As is common practice, the insurer first verified Mr. Tremblay's medical file. It found out that he was a carrier of the gene for myotonic dystrophy of Steinert, a serious neuro-degenerative genetic disease, and—more importantly—that he had been informed about his status before he applied for insurance coverage. The insurance company refused to pay out. When Ms. Audet, his surviving spouse, turned to the court to obtain coverage, the Québec Superior Court sided with the insurance company and declared the original insurance contract null and void.¹ Mr. Tremblay, according to the court, had made a fraudulent

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¹ *Audet v. Industrielle-Alliance*, [1990] R.R.A. 500 (C.S.).

declaration at the time of conclusion of the contract when he answered “no” to the question whether he had any “physical or mental anomaly.” It did not accept Ms. Audet’s explanation that he led a perfectly normal and healthy life at that time and that his disease was only very mildly expressed.

The case of *Audet v. Industrielle-Alliance* is the only known Canadian case involving the obligation to disclose genetic test results in the context of a life insurance contract and has therefore been cited in the few Canadian articles dealing with this topic.² Since the case raises interesting questions with respect to the extent of the duty to declare genetic test results in insurance applications, it is unfortunate that it was not appealed. An appeal of this decision would have focused on the extent of the duty to declare, and not on the more instinctive reason why so many people seem to object to its outcome. It would have provided an occasion to clarify the extent to which current insurance law allows insurers to invoke knowledge of genetic traits as a basis for establishing a duty to disclose, and it would have indicated to what extent insurance law is able to accommodate the often very precarious and vague nature of predictive health information.

When I use this case to introduce the topic of insurance and genetics, people tend to respond that there is something inherently wrong, something ‘unfair’ with an insurance company refusing to pay out life insurance coverage because of a pre-existing health condition that is unrelated to the person’s actual cause of death. The unfairness, in this view, seems related to the fact that people are disadvantaged because of a condition that escapes their control. People tend to have less trouble, however, accepting that negative consequences, such as loss of insurance coverage, are attached to self-inflicted harms or ‘irresponsible’ behavior. This view of fairness clashes with the way insurers approach fairness in insurance. According to insurance commentators, insurance contracts are prototypes of contracts between two free contractual parties who agree that the core of the contract, insurance coverage against payment of a premium, is based on mutual exchange of full information about all potential risks. It is a contract to insure against uncertainty. Insurers argue that fairness actually requires them to differentiate people on the basis of all risk information. People expect to pay premiums that are in accordance with their risk status. Forcing people who are at low risk to pay the same premium as people who are at high risk because this risk is related to a condition that escapes their control would in this view be unfair. It would

² See T. Lemmens, “Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?” (2000) 45 McGill L.J. 347 at 353-354, 401 [“Selective Justice”]; T. Lemmens & P. Bahamin, “Genetics in Life, *supra* note * at 139, 194; H. Guay, B.M. Knoppers & I. Panisset, “La génétique dans les domaines de l’assurance et de l’emploi” (1992) 52 R. du B. 185 at 209-210.

violate the nature of the contract people voluntarily agreed to enter into. Without knowing this beforehand, people at low risk would be cross-subsidizing risk coverage for those at high risk. Whether the risks that are the reason for the higher premiums are within people's control or not is, in this view, irrelevant.

Indeed, the common view of fairness in insurance, as reflected above, seems to clash with strict insurance law. Insurance commentators are right in stating that whether or not people control their condition is irrelevant to the determination of insurance premiums and disclosure obligations. Mr. Tremblay's potential 'fault' or personal contribution to the condition seems, indeed, not something insurance law is concerned about. The following analysis of insurance law in the context of genetics indicates, however, that policy considerations and perhaps also underlying notions of fairness have an impact on the interpretation of various obligations of contractual parties in an insurance contract. Even if current insurance law is generally not in line with what I described as a 'common' view of fairness, policy considerations—in particular concerns about the imbalance of the contractual relations—may explain a rather flexible interpretation of specific provisions dealing with disclosure obligations.³ After discussing the potential impact genetics is likely to have on insurance and the concerns raised by its use, I will discuss various cases that reflect a concern within the courts for the interests of consumers in the application and interpretation of insurance law. I will indicate how insurance provisions and the case law based on them can be used by those who are at risk of being excluded from insurance coverage on the basis of genetic test results. I will indicate the various obligations parties in an individual life insurance contract have with respect to genetic information.

II. New Genetic Developments and Insurance

This clarification of disclosure obligations related to genetics is timely. Although there have been few legal cases involving genetic testing and insurance in Canada or elsewhere, concerns about its implications for insurance coverage remain cited as one of the primary reasons why people are worried to undergo genetic testing or to participate in genetic research.⁴

³ This paper will not discuss in detail the debate around fairness and insurance discrimination. I have discussed this in other publications and I am developing another paper in which I analyze in detail how human rights approaches to the use of genetic testing deal with fairness concerns ("Selective Justice" *supra* note 2; and T. Lemmens, "Private Parties, Public Duties? The Shifting Role of Insurance in the Genetics Era" in A. Thompson & R. Chadwick, eds., *Genetic Information: Acquisition, Access, and Control* (New York: Plenum Press, 1999) 31.) This paper, however, looks at the more technical determination of how the courts have interpreted current insurance law provisions related to disclosure obligations, and how these cases inform us about obligations related to genetic information.

I have joined several other commentators in the past in arguing that the use of genetic testing was going to increase in the near future, augmenting the pressure on insurance companies to start using this new technology, and increasing concerns about genetic discrimination.⁵ While this prediction has not fully come true yet, there are reasons to expect that this will change. The technology of genetic testing is becoming more sophisticated, one of the promising developments being the development of gene chip technology that allows for simultaneous genetic testing for a variety of genetic mutations.

DNA chip technology is revolutionizing genetic testing. It will speed up diagnostic testing through which genes are analysed for variations of specific disease-causing alleles, and it will also permit testing for a variety of genetic mutations at the same time. Although the implications of the technology are still not fully clear, major breakthroughs are to be expected in the near future. A private company recently announced that it developed a microarray capable of analysing the products of all the 30,000 genes of the human genome on a single chip, while other companies are speeding up their research to be able to offer the same product.⁶

These developments, in particular when associated with fierce competition, is bringing down the cost of testing and may make it cost-efficient in the future to scan genetic material of, for example, insurance applicants, for a variety of genetic conditions and susceptibilities to disease. For Curtis R. Naser, there is no doubt that “[h]igh speed, inexpensive testing [...] radically tips the precarious balance [...] between the competing interests of insurers and insured.”⁷ The fast pace of the development of new genetic technology makes it highly probable that genetic testing will soon be marketed directly to the customer and that as

⁴ See e.g. K. Armstrong *et al.*, “Life insurance and breast cancer risk assessment: adverse selection, genetic testing decisions, and discrimination” (2003) 120:3 *Am. J. Med. Genet.* 359.

⁵ “Selective Justice”, *supra* note 2 at 351 and references there.

⁶ See A. Scott, “The Human Genome Will Soon Be Joined By Rivals.” *BioMed Central* (13 October 2003) online: <<http://www.biomedcentral.com/news/20031003/07>> (date accessed: 20 October 2003); and M. Addonizio, “The Great Chip Chase” *The Scientist* 17:17 (8 September 2003) 49. For other articles on gene chip technology, see K.M. Kurian, C.J. Watson & A.H. Wyllie, “DNA Chip Technology” *Editorial Comment* (1999) 187 *J. Pathol.* 267. For a discussion of potential legal and ethical implications, see C.R. Naser, “High Speed Genetic Testing Technology and the Computerization of the Medical Record” in Thompson & Chadwick, *supra* note 3, 105; W. Henn, “Genetic Screening with the DNA Chip: A New Pandora’s Box?” (1995) 25 *J. Med. Ethics* 200; and Council on Ethical and Judicial Affairs, American Medical Association, “Multiplex Genetic Testing” (1998) 28:4 *Hastings Ctr R.* 15.

⁷ *Ibid.* at 110.

with HIV/AIDS, people will be able to control the type of testing they undergo. For that reason, the U.K. Human Genetics Commission launched in 2002 a consultation document to involve the public in a discussion of the legal and ethical issues raised by this development.⁸

Genetic analysis is already increasingly integrated in clinical practice. Pharmacogenetic research will very likely increase the use of genetic testing in clinical practice.⁹ This research focuses on determining the link between the genetic profile of individual patients and drug response. It is based on the accepted premise that genetic variation among individuals explains why drugs have different side effects and differ in terms of efficacy among patients. Research increasingly focuses on finding genetic clues that can explain and predict these differences. If and when pharmacogenetics is integrated into clinical practice, the genetic profiling of individuals will likely become an essential part of determining an appropriate drug therapy. It is too early yet to predict what impact these developments will have on insurance, and in particular on life insurance. But some scenarios make it clear that it may increase the pressure on insurance companies to start using these technologies and to conduct individualized risk assessments through the use of predictive genetic technology. Genetic testing may enable the prediction not only of the chances that individuals will develop a specific disease, but also of the efficacy of a specific drug and the likelihood of negative side effects. This would clearly be relevant for individual health insurance contracts offering drug coverage, for example. If individuals have genetic profiles that indicate that they are likely to respond well to an existing common drug, insurers have a clear incentive to offer them lower premiums than those whose genetic profile indicates the contrary. This result of pharmacogenetic research may even be amplified by the potential link of pharmacogenetics and the evolution of drug prices. Since drugs targeting less common genetic profiles will have a smaller potential market, they will not be a research priority for pharmaceutical companies and their price will likely be higher than the drugs that have an impact on more commonly shared genomic profiles. In addition to the concept of orphan diseases, we may see the development of the concept of orphan genomes, i.e. marginal genomic structures that receive less attention by mainstream medical researchers and industry.

Individuals could certainly be inclined to use their genetic dossier to

⁸ U.K., Human Genetics Commission, *The Supply of Genetic Tests Direct to the Public: A Consultation Document* (London: Human Genetics Commission, 2002), online: Human Genetics Commission <<http://www.hgc.gov.uk/testingconsultation/>> (date accessed: 5 August 2002)

⁹ See e.g. A.D. Roses, "Pharmacogenetics and the practice of medicine" (2000) 405 *Nature* 857.

negotiate a better premium for their insurance contracts. And those with a less favourable genetic profile could be singled out for higher drug plan premiums. Although the link between drug insurance plans and pharmacogenetics is more obvious, these developments can also have a significant impact on life insurance contracts, which are the subject of this article. Combined with an increase in clinical predictive genetic testing, pharmacogenetics testing may offer additional information about the chances that people with a specific genetic profile will react positively to therapy when they become ill. People who test positive for one of the breast cancer genes, for example, and who would be normally charged a higher premium for that reason,¹⁰ may in the future be able to indicate to insurers that they are likely to respond well to existing treatment due to their distinct genetic profile. They would thus be able to obtain a reduction of their premium compared to someone who tests positive and who does not have the same profile.

Given these developments, it is particularly interesting at this stage to consider how current insurance law would deal with disclosure obligations related to genetic testing. First of all, since it can be expected that this technology will be of interest to insurers—certainly when it will be more integrated in clinical practice—a discussion of potential disclosure obligations will help to predict the outcomes of legal cases. Secondly, genetics is still very much in the research stage, which adds to the fact that genetics inherently involves an element of uncertainty. The results of genetic research are often difficult to understand. During the process of scientific validation of early research results, few data will be available to validate claims about the predictive nature of genetic test results. This can continue for a significant period of time. As I will discuss further, these factors create an interesting context for the discussion of the extent of disclosure obligations. There is an ongoing debate in insurance law about the duty to disclose clear risk information. Discussing the extent of this obligation becomes even more interesting when it requires a determination of the reasonableness and solidity of experimental knowledge.

¹⁰ Since BRCA1&2 testing is one of the most widely used genetic tests at this time, it has been the subject of some debate in the context of insurance. Actuarial specialists have studied the potential effect on the insurance industry of not using the information provided by these genetic tests. Interestingly, their conclusion was that its impact would not be significant and that the adverse selection costs resulting from not providing access to genetic testing could be controlled by insurers as long as correct family histories were used in the underwriting process. This undermines the claim by insurers that they need access to these test results to avoid the collapse of the insurance industry. See K. Subramanian *et al.*, “Estimating Adverse Selection Costs From Genetic Testing for Breast and Ovarian Cancer : The Case of Life Insurance.” 1999 (66) *J. Risk and Insurance* 531. See *infra* notes 91-93 and accompanying text for a discussion of the concept of adverse selection.

III. *What is Genetic Testing?*

My analysis focuses on the use of genetic test information. This requires some clarification. While the development of new genetic technologies has revolutionized medicine and led to a novel understanding of biology and human health, the idea that hereditary factors contribute to disease and premature death obviously predates this development. Sketching out family histories of disease as part of a diagnostic process has been common practice in medicine for a long time. For medical conditions such as breast cancer and heart disease, it was commonly understood that when several ancestors or close family members had developed the illness, chances were high that others in the family would develop it too. As I will discuss further, family histories have therefore been a core component of the underwriting practice in insurance. In other words, insurance companies have traditionally used 'genetic information' to determine premiums.

The use of family histories, however, will not be the subject of my article. I do not want to suggest that the use of family histories of illness is inherently unquestionable and can be entirely separated from the debate about the use of genetic test information in insurance. Indeed, as I have discussed elsewhere,¹¹ countries that have introduced a strict ban on the use of genetic testing have been confronted with the contradiction of prohibiting insurers to use a genetic test result as a factor in underwriting, while leaving traditional underwriting practice, involving similarly predictive family histories of genetic disease, untouched. In these countries, people who have a family history of a condition for which no precise genetic test has been developed can be charged a higher premium, while those who have tested positive for a genetic condition indicating a similar risk for pre-mature death or disease are protected against such increase. Some of the legislative schemes that have created a schism between the treatment of family history and genetic test results have also clearly limited the potential positive use of genetic test results for those affected by a family history of genetic disease. This seems to contradict the purpose of the legislation, *i.e.* the protection against genetic discrimination. In Belgium, for example, the very stringent insurance law provisions dealing with genetic testing led to a situation whereby those who are excluded from insurance coverage because of a family history of Huntington's disease cannot submit a genetic test result indicating that they do not carry the deleterious gene and are not at risk.¹² The goal of the prohibition on the submission of genetic test results is to prevent insurers from doing indirectly what they cannot do directly: if they are only

¹¹ See "Selective Justice" *supra* note 2 at 359-61, 367-68.

¹² See *Wet 25 juni 1992 op de landsverzekeringsovereenkomst*, B.S. 20 August 1992, art. 5: "Genetische gegevens mogen niet worden meegedeeld" (Genetic data may not be declared.).

prohibited from imposing genetic testing as a precondition for insurance, they could indeed circumvent this prohibition by offering rebates to people who freely submit to genetic testing. Yet, it seems unfair and contrary to the statute's goal of protecting against genetic discrimination that these provisions result in people being stuck with their family history of disease even if genetic tests indicate that they are not at risk for developing the disease.

This paper, however, focuses on an analysis of disclosure obligations under existing insurance law in the context of information related to new genetic testing technologies. It discusses neither the rationality of issuing genetic-specific legislation nor the use of human rights law in the context of insurance. Other policy options are discussed only briefly. An analysis of the potential human rights initiatives in this area could not avoid a discussion of the similarities between family history and genetic test results. This paper, however, singles out a specific aspect of insurance law, where questions arise with respect to the potential disclosure obligations in the context of research and new forms of genetic testing. Disclosure obligations related to family history are clear; they have been around for a long time.

The information gained from the use of genetic testing is often complex and not well understood by individual applicants, their physicians and insurance experts. Moreover, it is often still uncertain and subject to further scientific validation. The discussion highlights how insurance law provisions, in particular those related to disclosure obligations, apply in the context of scientific uncertainty and change, brought by the introduction of novel technologies in medicine.

I will therefore focus on the use of genetic test results in insurance. But what counts as genetic testing or as genetic test results? This question is difficult to answer. Many statutes or legislative proposals have struggled with this issue.¹³ In most discussions, genetic information is understood as information resulting from the analysis of an individual's DNA. Startling developments in molecular genetics and DNA technology over the last decades are directly responsible for what has been termed "the genetic revolution." When people talk about "genetic information," they are usually thinking of information derived from the use of this new technology. Through the use of a variety of techniques such as electrophoresis, somatic cell hybridization, cytogenetic mapping, multiplexing, and radiation-induced breakage of chromosomes, scientists have been able to make physical maps of the human genome. The physical maps portray the position, size, order and numbering of base pairs in the different genes. Comparison of the maps of different people allows

¹³ See e.g. G.J. Annas, L.H. Glantz & P.A. Roche, *The Genetic Privacy Act and Commentary* (Boston: Boston University School of Public Health, 1995) at 45.

researchers to find specific mutations associated with genetic conditions or traits. Even when the mutation directly related to a genetic condition has not been identified, DNA techniques can be used to find markers for the disease. Markers are characteristic DNA sequences that enable scientists to determine whether a mutation present in that DNA region has been inherited or not.

A variety of tests have been developed on the basis of these techniques. Currently, DNA-based genetic tests are available for: Amyotrophic lateral sclerosis (Lou Gehrig's disease), hereditary Alzheimer's disease, ataxia telangiectasia, inherited breast and ovarian cancer, Cystic Fibrosis, Duchenne muscular dystrophy, fragile X syndrome, Huntington's disease, myotonic dystrophy, sickle cell disease, thalassemia, Tay-Sachs disease and several other conditions.¹⁴

Although some of the most spectacular advances in medicine have been obtained by DNA analysis, other forms of testing can clearly be identified as "genetic tests." Testing can also occur at the chromosomal level. Chromosomal abnormalities can be detected, for example, through amniocentesis. Other forms of "genetic tests" involve the testing of urine, blood or other body fluids to discover abnormal metabolite levels that are indicators of genetic disorders such as phenylketonuria (by measurement of phenylalanine in blood) or Lesch-Nyhan disease (by identification of high uric acid levels). Finally, genetic disorders can be detected through measuring proteins, which are the products of genes. Defective genes often lead to identifiable deficiencies in protein production. The observation of mutant proteins can be used to determine the presence of a genetic condition such as Tay-Sachs. The analysis of protein function, and the interaction between genes and protein production, is increasingly emphasized as key to understanding the development of disease. These forms of genetic testing will probably become more common and could very well be more clinically relevant than traditional forms of genetic testing mentioned above.

The Australian Investment and Financial Services Association, a

¹⁴ For a list of tests, see Ontario, Provincial Advisory Committee on New Predictive Genetic Technologies, *Genetic Testing Services in Ontario: Mapping the Future* (Toronto: Queen's Printer, 2002) at 87-88. Other reports also contain lists of tests. See, among others: Australia, Australian Law Reform Commission & National Health and Medical Research Council, *Essentially Yours Report: The Protection of Human Genetic Information in Australia*, Report 96, vol. 1 (Sydney: Australian Law Reform Commission, 2003) at 123-127 [*Essentially Yours*]; and U.K., Human Genetics Commission, *Whose hands on your genes: A discussion document on the storage protection and use of personal genetic information* (London: Human Genetics Commission, 2000) at 10, online: Human Genetics Commission <http://www.hgc.gov.uk/business_consultations2maintext.pdf> (date accessed: 15 October 2003).

professional organization representing life insurers in that country, gives a definition of the term ‘genetic test’ as part of its policy statement on the use of genetics in underwriting. It defines it as “the direct analysis of DNA, RNA, genes or chromosomes for the purpose of determining the inherited predisposition to a particular disease or group of diseases, but excluding DNA, RNA, gene or chromosome tests for acquired disease.”¹⁵

While I have sketched here the type of tests that can be developed on the basis of new biomedical research, it is not necessary for the purpose of this discussion to formulate a precise definition. The analysis here is concerned with how genetic information derived from novel biomedical technologies creates disclosure obligations under current insurance law in Canada. It focuses, in other words, on how one very precise set of legal rules (disclosure rules in insurance law) applies in the context of the new genetics, how these rules create obligations, and how these rules have been interpreted rather flexibly in the courts in a way that provides protection to insurance applicants.

The Australian Law Reform Commission and the National Health and Medical Research Council, in their 2003 report on the protection of genetic information, have also avoided giving a clear definition of genetic testing. As they state, their report “is concerned with the protection of genetic information, however it may be derived” and they do not “consider it necessary to propose a comprehensive definition of what a genetic test is.”¹⁶ The drafters of the report argue that the meaning of genetic testing and genetic information may vary, depending on the context of the debate.

IV. Framing the Debate: What is a Life Insurance Contract?

This article looks at the use of genetic test results in the context of life insurance. As will become clear from the discussion, new genetic technologies could have particular relevance for this form of insurance. While American publications have mainly focused on the use of genetics for health insurance purposes, Canada shares with most other industrialized countries the existence of a publicly funded health care system. Genetic testing might also eventually be used in the context of private, additional health care contracts and private drug plans, but this is unlikely in the immediate future, simply because in Canada, these forms of insurance are generally offered through group insurance plans which do not involve an underwriting process.

¹⁵ IFSA Standard 11.00: ‘Genetic Testing Policy’ (2002), cited in *Essentially Yours*, *ibid.* at 322.

¹⁶ *Essentially Yours*, *ibid.* at 323. See also *ibid.* at 130; U.K., Human Genetics Commission, *Inside Information: Balancing Interests in the Use of Personal Genetic Data* (London: Department of Health, 2002) at 27.

It is important, for a good understanding of the analysis, to indicate the main characteristics of a life insurance contract. Insurance is generally divided into the following large groups: fire insurance, automobile insurance, marine insurance, life insurance, accident and sickness insurance, and health insurance.¹⁷ Forms of insurance other than life insurance provide coverage for a variety of potentially subsequent events. Coverage, in other words, generally continues after the risk for which it provides coverage has materialized. These contracts can also involve an adjustment of the contract based on external factors, for example on the changed risk profile of the insured; and they generally have to be renewed explicitly, at which time new conditions and contractual terms may have to be negotiated. A life insurance policy aims at the payment of a benefit at the time of death of the life insured, which is a one-time event.¹⁸ A distinctive characteristic of life insurance is that — except for rare cases, for example when people disappear — it is clear when the risk — death — has occurred. The only uncertainty of the contract is the time of this death.¹⁹ However, extra benefits can be based on the manner of death. Extra money might be paid, for example, in cases of accidental death. Another characteristic is that the risk in life insurance contracts is determined at the time of the conclusion of the contract. Subsequent changes to the risk profile do not, in theory, affect the nature of the contract. This has important implications in the context of novel medical technologies. Changes in scientific findings that occur after the contract has been signed do not interfere or change the contractual rights and obligations embedded in life insurance contracts.

Life-insurance policies are often the foundations of more elaborate contracts that include many additional benefits. They might be linked to mortgages or other contracts. Mortgage contracts for buying houses or starting businesses are often provided only if accompanied by life-insurance contracts.

Life-insurance contracts are often also connected to a form of “disability insurance.” Disability insurance can be defined as a benefit, by which “the insurer undertakes to pay insurance money or to provide other benefits in the event that the person whose life is insured becomes disabled as a result of bodily injury or disease.”²⁰ Disability insurance includes a “disability waiver of premium.” The latter is a clause linked to a life-

¹⁷ C. Brown & J. Menezes, *Insurance Law in Canada*, vol. 1, looseleaf (Toronto: Carswell, 2002) at 1-12. For a more exhaustive list of classes of insurance established under the Ontario *Insurance Act*, R.S.O. 1990, c. I-8 [*O.I.A.*], see M.G. Baer & J.A. Rendall, *Cases on the Canadian Law of Insurance*, 6th ed. (Scarborough, Ont.: Carswell, 2000) at 99-100.

¹⁸ D. Norwood & J.P. Weir, *Norwood on Life Insurance Law in Canada*, 2nd ed. (Toronto: Carswell, 1993) at 63.

¹⁹ Brown & Menezes, *supra* note 17 at 1-1.

insurance contract in which the insurance company agrees to waive the payment of premiums in case the applicant becomes disabled. Another term that one frequently finds in the context of life insurance is “family insurance.” Family insurance refers to

insurance whereby the lives of the insured and one or more persons related to the insured by blood, marriage or adoption are insured under a single contract between an insurer and the insured.²¹

This form of insurance is thus a qualification of a life insurance contract (insurance coverage for several family members at the same time) and not a different form of insurance.

Insurance can be bought either individually or under a group plan. An individual policy is a contract between the insurer and a specific individual, usually the person insured. A group policy is a contract between the insurer and a “group policyholder,” insuring the lives or health of many people.²² The latter have some connection with the group policyholder — often an employer, trade union, or professional association. Under a group plan, those insured are not named or otherwise identified as individuals. Furthermore, as third-party beneficiaries, they have no rights except those given to them under the contract signed by the policyholder or “sponsor.”²³ More and more personal insurance — such as life, health, and accident insurance — is now in the form of group insurance.²⁴ The difference between group insurance and individual insurance is significant for the present discussion. For group insurance, underwriting is usually limited and the only questions asked relate to age, sex, prior insurance claims, and some other administrative details. People can adhere to the plan, most often without distinction based on health or risk status. For individual insurance, however, underwriting is often much more detailed.²⁵ The subsequent discussion, as already pointed out, focuses on life insurance, and in particular life insurance contracts that involve some form of underwriting, which is generally not the case for those obtained through

²⁰ *O.I.A.*, *supra* note 17, s. 1.

²¹ *Ibid.*, s. 171; *Insurance Act*, R.S.A. 2000, c. I-3, para. 554(f) [A.I.A.]; *Insurance Act*, R.S.B.C. 1996, c. 226, s. 29 [B.C.I.A.]; *Insurance Act*, R.S.M. 1987, c. 140, s. 148(1) [M.I.A.]; *Insurance Act*, R.S.N.B. 1973, c. I-12, s. 132 [N.B.I.A.]; *Insurance Act*, R.S.N.S. 1989, c. 231, para. 64(h) [N.S.I.A.]; *Insurance Act*, R.S.P.E.I. 1988, c. I-4, para. 119(h) [P.E.I.I.A.]; *Saskatchewan Insurance Act*, R.S. 1978 c. S-26, para. 133(f) [S.I.A.]; *Insurance Act*, R.S.N.W.T. 1988, c. I-4, s. 69 [N.W.I.A.]; *Insurance Act (Nunavut)*, R.S.N.W.T. 1988, c. I-4, s. 69 [N.I.A.]; *Insurance Act*, R.S.Y. 2002, c. 119, s. 76 [Y.I.A.].

²² Norwood & Weir, *supra* note 18 at 65.

²³ *Ibid.*

²⁴ *Ibid.*

²⁵ R.J. Pokorski, “Insurance Underwriting in the Genetics Era” (1997) 60 *Am. J. Hum. Genet.* 205 [hereinafter “Insurance Underwriting”].

group insurance.

As other forms of private insurance, a life insurance contract is “a private contract in which one party, the insured, transfers certain risks of loss to another, the insurer, for monetary considerations.”²⁶ Norwood and Weir define the contract as “a binding obligation to pay or perform upon the happening of a specified contingency.”²⁷ By signing an insurance contract, applicants agree to pay premiums, which are specific amounts of money, usually paid at regular intervals. Insurers promise to pay out specific amounts for compensation in case of specified events, which in the context of life insurance is the death of the person insured.

The most particular element of an insurance contract, and an essential component of it, is the concept of risk.²⁸ As François Ewald posits, “[w]ithout it, insurance would not be possible.”²⁹ An insurance contract implies uncertainty. Both parties enter an insurance contract without knowing exactly how much they will contribute or benefit. Those insured might pay premiums for a very long time without receiving any benefit other than the certainty that, if the risk for which they are covered occurs, they will be compensated. Insurers enter into insurance contracts without knowing for certain how much they will have to pay, if anything, in compensation. Insurance is intended to create controlled uncertainty. Craig Brown and Julio Menezes describe insurance as “a mechanism for spreading the risk of loss.”³⁰ For applicants, potentially devastating risks are replaced by the risk of paying many premiums without ever receiving compensation or without receiving an equal amount of compensation. They spread what they consider a serious risk into a calculated and affordable risk, one that does not substantially affect their standard of living. The advantage of insurance, for applicants longing for some form of control over their financial situation, is that catastrophic losses at an unpredictable time are replaced by more modest regular financial sacrifices. These sacrifices are the price that they are willing to pay for financial security.³¹

Insurers, for their part, spread the risk of having to pay out major

²⁶ *Black's Law Dictionary*, 6th ed., s.v. “insurance”.

²⁷ Norwood & Weir, *supra* note 18 at 17.

²⁸ A. Besson et M. Picard, *Les assurances terrestres en droit français de M. Picard et A. Besson*, t. 1, 5th ed. (Paris: L.G.D.J., 1982) at 34; D. Lluelles, *Précis des assurances terrestres*, 3rd ed. (Montréal: Editions Thémis, 1999) at 169.

²⁹ F. Ewald, “Genetics, Insurance and Risk” in T. McGleenan, U. Wiesing & F. Ewald, eds., *Genetics and Insurance* (Oxford: BIOS Scientific Publishers, 1999) 17 at 21.

³⁰ Brown & Menezes, *supra* note 17 at 1-1.

³¹ N. Daniels, “Insurability and the HIV Epidemic: Ethical Issues in Underwriting” (1990) 68:4 *Milbank Q.* 497 at 501. See also P. Sandberg, “Genetic Information and Life Insurance: A Proposal for an Ethical European Policy” (1995) 40:11 *Soc. Sci. Med.* 1549 at 1554.

amounts by having a pool of insured people, all of who contribute to the system and are unlikely to make claims simultaneously. Insurance companies are submitted to rigorous rules about the amount of liquid assets they have to keep at any time to fulfill potential demands for reimbursements by people insured. Moreover, insurance companies reinsure the total sum of their insurance contracts with other, specialized insurance companies. This provides additional protection against the unlikely event that they have to pay out too much at the same time. Overall, contributions from the pool of clients (or profits from investments based on these contributions) must be greater than the total sum of insurance claims of any given time in order to have a lucrative insurance company and to stay in business.³²

The technical term for spreading insurance premiums over different applicants and according to risk groups is “pooling the risk.”³³ In such risk pools, people contribute according to the risk they represent. The total cost of the risk insured is thereby distributed between the members of the pool, and according to the level of risk the people in a particular pool represent.³⁴ As Pokorski puts it, “policyholders pay a relatively small, affordable amount into a common ‘pool,’ and the benefits of the pool are distributed to the unfortunate few who die (life insurance), become disabled (disability insurance), or become sick (health insurance).”³⁵ Didier Lluelles suggests that, in a way, policyholders themselves pay the claims and insurers are only intermediaries. The latter have the task of administering the money paid by members of the risk group.³⁶ This view emphasizes even more how members of the group expect to contribute according to the risk they represent.

V. *Underwriting and Life Insurance*

A. *What is Insurance Underwriting?*

Underwriting is a crucial part of risk pooling and a fundamental element in insurance. It is in this underwriting process that genetic testing could play a role.³⁷ Underwriting is the method used to classify people according to risk. Since people are required to pay premiums commensurate with the

³² Daniels, *ibid.*

³³ Brown & Menezes, *supra* note 17 at 1-2.

³⁴ Ontario Law Reform Commission, *Report on Genetic Testing* (Toronto: Queen’s Printer, 1996) at 7.

³⁵ R.J. Pokorski, “Use of Genetic Information by Private Insurers” in T.F. Murphy and M.A. Lappé, eds., *Justice and the Human Genome Project* (Berkeley: University of California Press, 1994) 91 at 91 [hereinafter “Use of Genetic Information”].

³⁶ Lluelles, *supra* note 28 at 4.

³⁷ H.D.C. Roscam-Abbing, “Predictive Genetic Knowledge, Insurance and the Legal Position of the Individual” in Swiss Institute of Comparative Law, ed., *Human Genetic*

risk they represent, insurers must evaluate and classify the risk and calculate the appropriate corresponding premium. Various factors are taken into consideration in this process. People's life expectancies are quantified and expressed as statistical probabilities. Risk classification is based on the differences that exist among them. Various studies confirm that the risk predictions for all the people in a specific pool in insurance underwriting are quite accurate.³⁸ Underwriting allows insurers to predict the overall mortality rate of a specific group of people, classified in the same risk category, in comparison with the average population.

Three different risk groups are generally distinguished: 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 are insurable, but they 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.³⁹ Insurance contracts frequently exclude from coverage death as a result of suicide, or specify that such death will not be covered if it occurs within a specified period of time, usually two years, after the conclusion of the contract. The *Uniform Insurance Act*, which represents the common statutory insurance provisions of the Canadian common law provinces, specifies that if an insurance contract "contains an undertaking, express or implied, that insurance money will be paid if a person whose life is insured commits suicide, the undertaking is lawful and enforceable."⁴⁰ This provision was intended to counterbalance an English decision, in which it was considered against public policy for an insurance company to pay out following a suicide.⁴¹

In the leading case of *Frenette v. Metropolitan Life Insurance Co.*,⁴² an insurance company sought to obtain access to the medical records of a man found in the Ottawa River, in order to determine whether he died as a result of suicide or the consumption of illicit drugs, two causes of death which

Analysis and the Protection of Personality and Privacy, International Colloquium (Zürich: Schulthess Polygraphischer Verlag, 1994) 143 at 146.

³⁸ "Insurance Underwriting", *supra* note 25 at 206.

³⁹ See NIH/DOE Working Group on Ethical, Legal and Social Implications of Human Genome Research, *Genetic Information and Health Insurance*, HHH Pub. no. 93-3686 (Washington, DC: Human Genome Project, 1993), online: National Human Genome Research Institute <<http://www.genome.gov/10001750>> at 16 [NIH/DOE report].

⁴⁰ *O.I.A.*, *supra* note 17, s. 188(1). For an explanation of the term *Uniform Life Insurance Act*, see *infra* notes 116-120 and accompanying text.

⁴¹ B.R. McDonald, *Life and Disability Insurance Laws in Canada (Common Law Provinces)* (Toronto: Canadian Association of Insurance and Financial Advisors, 2000) at C9-10.

⁴² [1992] 1 S.C.R. 647 [*Frenette*].

were expressly excluded from coverage.⁴³ Insurers incorporate such clauses to protect themselves against suicidal people who might hope to conclude very lucrative insurance contracts for their offspring.

Some people with a family history indicative of susceptibility to a serious genetic condition 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 that would cover any unexpected death unrelated to the disease.

The underwriting process can be described as proceeding in three steps: in a first phase, insurance companies gather information about the personal risk factors of applicants. In a second phase, they try to determine the degree of risk represented by these factors and classify an application in a pool corresponding to the level of risk. Finally, they determine the appropriate premium to be paid using one or more premium tables.⁴⁴

How detailed and complex these three steps will be for a specific insurance contract depends very much on the amount of coverage and on the type of insurance product. Some limited life insurance coverage, for example under \$ 100,000 can often be obtained without many questions asked and is generally based on very general distinctive characteristics such as the person's age and sex. Other 'no questions asked' policies, for example those targeting seniors, can be very expensive because the potential high-risk status of many of the applicants is taken into account in the calculation of the premiums. To obtain a reasonably priced life insurance contract providing substantial coverage, people generally have to undergo a detailed underwriting process.

Insurers now have a panoply of different sources of information at their disposal. Depending on the amount of coverage offered, insurance will make use of the following sources: insurance applicants, medical and hospital records, files of the Medical Information Bureau (MIB),⁴⁵ and medical tests imposed as part of the contract negotiations by insurers. These sources are used to obtain information about the following traditional factors: age, sex, health history, physical condition, occupation, alcohol and tobacco consumption, family history, and serum cholesterol.⁴⁶

The forms used in the underwriting process to gather that information

⁴³ For a more detailed discussion of the case in the context of access to medical records, see *infra* note 55 and accompanying text.

⁴⁴ Ontario, Legislative Assembly, Select committee on Company Law, *The Insurance Industry: Fourth Report on Life Insurance*, (Toronto: Queen's Printer, 1980) at 217.

⁴⁵ NIH/DOE report, *supra* note 39 at 16; J. Stengel & C. Brown, "The Impact of AIDS on the Canadian Life Insurance Industry" (1990) 2:1 C.I.L.R. 95 at 107.

⁴⁶ NIH/DOE report, *ibid.* at 92; Select Committee on Company Law, *supra* note 44 at 221.

become part of the overall contract in the same way as any specific conditions mentioned in the text of the contract. The *Uniform Insurance Act* and the *Civil Code of Québec*⁴⁷ provide that the life insurance contract consists of the policy itself and any documents attached to it, as well as any written amendment agreed upon afterwards.⁴⁸

B. Sources of Underwriting

1. Insurance Applicants' Declarations

Insurance applicants remain the first source of information used by underwriters.⁴⁹ As will be discussed further, insurance law obliges applicants to declare everything relevant to risk appreciation and classification. Life, disability, and health insurance focus on many elements usually known only to applicants, namely their overall health or the existence of specific risks.⁵⁰ When insurers ask specific questions to applicants, they create a binding contractual obligation to respond honestly to the question. The truthfulness of the answer, as will be discussed further, becomes an important aspect of the validity of the contract.

The insurance questionnaires used by insurers contain questions not only about people's health and life style, but also about their family history. As has frequently been pointed out, this is clearly a form of genetic information. The aim of these questions is to determine whether there are hereditary conditions that are more likely to affect people's longevity. This form of genetic information is one of the most traditional sources of information used for underwriting purposes. As I have mentioned earlier, several countries that have prohibited the use of genetic test information for insurance purposes have not banned the use of family histories, which seems inconsistent. Indeed, at this stage, a detailed family history of disease may tell us as much about a person's likelihood of premature death as many forms of genetic testing.

2. Medical Files

Medical files are obviously an interesting source of information for a contract that has as one of its core components the state of health of a person and that requires a determination of the person's risk for premature death. The information contained in these medical files is generally much more reliable and accurate than the information that is known and

⁴⁷ S.Q., c. 64 [the *Civil Code* or C.C.Q.]

⁴⁸ *O.I.A.*, *supra* note 17, s. 174(2); art. 2478, 2482 C.C.Q.

⁴⁹ N.C. Jecker, "Genetic Testing and the Social Responsibility of Private Health Insurance Companies" (1993) 21 J.L. Med. & Ethics 109 at 110.

⁵⁰ Lluelles, *supra* note 28 at 230.

understood by the applicant. In the context of a discussion on the impact of genetics on insurance practice, it is important to point out that genetics is increasingly becoming a part of standard medical practice, and that genetic test results are increasingly being recorded in medical files.⁵¹ These include traditional genetic tests such as those for single gene disorders, for example Huntington's disease, but also other forms of genetic tests, such as diagnostic protein tests, which are gradually being integrated into mainstream medicine.

It is often through access to medical and hospital records that insurance companies become aware of genetic information.⁵² Insurance companies have always been interested in access to such records. Lori Andrews suggested in a 1987 publication that "[t]he majority of medical records in third party hands are those in possession of insurers."⁵³ Insurers traditionally ask applicants for permission to examine their medical charts.⁵⁴ An insurance application form traditionally also contains a waiver of confidentiality. By signing the application, applicants explicitly authorize insurers to access their medical files. Since this is generally one of many clauses, applicants often may not be fully aware of the implications of signing this waiver. The permission granted allows insurers to verify the health of applicants and to make sure that the amount of protection requested is not inordinately high in light of their health status. Although they could use this clause for verification purposes at the time of application, insurers often only request access when a claim is made.

Following the Supreme Court's decision in *Frenette*,⁵⁵ insurance companies can easily obtain access to medical files. The right to confidentiality of medical records, according to the court in *Frenette*, can be waived without restriction as to scope or time. The extent of the right of access will depend on the wording of the contract containing the waiver,

⁵¹ Jecker, *supra* note 49 at 110; Ontario Law Reform Commission, *supra* note 34 at 105.

⁵² Jecker, *ibid.* at 112.

⁵³ L.B. Andrews, *Medical Genetics: A Legal Frontier* (Chicago: American Bar Foundation, 1987) at 205.

⁵⁴ Guay, Knoppers & Panisset, *supra* note 2 at 214.

⁵⁵ *Supra* note 42. The *Frenette* case involved a young man whose body was found in a river. It had been impossible to discover through autopsy whether Mr. Frenette died from suicide or from a fatal reaction to illegal drugs. Both suicide and death resulting from unprescribed drugs had been explicitly excluded from coverage. The insurance company wanted access to the medical files to prove its case. It knew Mr. Frenette had received psychiatric care in the past and that he had been treated in the hospital on the night of his disappearance. When he applied for insurance, Mr. Frenette had signed a consent form granting access to all his medical files. The waiver of confidentiality he signed was unlimited in time, but the hospital refused access to the files, invoking its own policy, according to which a more recent consent was required.

and on the nature and scope of the release form.⁵⁶

The implications of this case are significant in the context of genetic research. For some time, genetic researchers have been confronted with concerns among research subjects about the potential insurance implications of participating in genetic research. In reaction to this concern, a practice has developed among many genetic researchers to keep a separate genetic research file, and to avoid any cross-references in the medical file to the genetic research, even if some of the information could be clinically relevant. The Supreme Court, however, clearly stated that unlimited waivers have to be respected. This suggests that mere reference in a waiver to “all medical and hospital records” forces those institutions in which the research took place to provide access to insurers to these genetic research files for purposes of risk assessment.

It is also worth pointing out that the Supreme Court made a distinction between disclosure of medical information in judicial and extrajudicial contexts.⁵⁷ In the latter context, it ruled, courts must broadly interpret the general duty of non-disclosure imposed on hospitals and medical professionals and interpret restrictively any violation of the right to confidentiality.⁵⁸ In a judicial context, the duty of secrecy among professionals, such as physicians, is translated into an evidentiary privilege.⁵⁹ This means that physicians may refuse to divulge confidential information in judicial proceedings unless the court considers this at odds with the administration of justice. On this basis, L’Heureux-Dubé J. mentioned, *in obiter*, that even without consent, courts could order access to medical files, “where the state of the health of the holder of the privilege is the central issue of the case and where there are no other means for a party to prove his case.”⁶⁰ Life, disability and sickness claims are nearly always linked to the health of the claimant. Following L’Heureux-Dubé

⁵⁶ As in any standard insurance contract, the waiver signed by Mr. Frenette, the insurance applicant, stipulated that he authorized access to all medical and hospital records for “the purposes of risk assessment and loss analysis.” No other limits were stipulated. L’Heureux-Dubé J., writing for a unanimous court, concluded that this contractual waiver entitled the insurer to have access to the *complete* medical records, because the only condition attached to it was that it be used for the purposes of “risk assessment and loss analysis.” *Ibid.* at 672. The Supreme Court clearly did not follow the Court of Appeal’s objection against general access, which was that general access provisions offered insurance companies the opportunity to go on a “fishing expedition.” *Zurich Insurance Co. v. Ontario (Human Rights Commission)* (1989), 70 O.R. (2d) 639 (C.A.).

⁵⁷ For a more detailed discussion of this case in the wider context of compelled disclosure of medical records in judicial procedures, see J. Dawson, “Compelled Production of Medical Records” (1998) 43 McGill L.J. 25, in particular at 60-63.

⁵⁸ *Supra* note 42 at 675.

⁵⁹ *Ibid.*

⁶⁰ *Ibid.* at 685-686.

J.'s opinion, insurers have nearly unlimited access to their insured's medical files.

This allows insurers to investigate whether clients have neglected to mention that they are carriers of genetic disorders or that such disorders run in the family. The *Frenette* decision makes it possible for insurance companies to obtain access to the medical records even if no waiver of confidentiality was given. Insurers can simply refuse to pay out and wait for court procedures in order to try to find evidence of false declarations that could be used to annul the contract.

3. *The Medical Information Bureau*

The MIB is another important source of information. The MIB is a non-profit association of more than 700 insurance companies operating in the United States and in Canada.⁶¹ It functions as a central data bank for medical information on insurance applicants and it also compiles actuarial statistics that can be used for mortality and morbidity related studies.⁶² When people apply for insurance coverage to a member of the MIB, the insurance form they sign contains an explicit clause that allows insurance companies to enter information on their application in the MIB database and to verify information they provide with information contained in the database. Insurance companies thus use the MIB to vet information given by applicants, and at the same time, feed the MIB database with the information they obtain in the underwriting process.⁶³ This procedure allows insurance companies to determine, for example, whether or not potential clients have already applied to other companies for insurance and what risk factors they have been associated with. Insurance companies can use this information to evaluate applicants' insurability.

The MIB does not store complete medical records or insurance files. According to J. Alexander Lowden, formerly medical director of a major insurance company, MIB records do not specify whether insurance has been denied by other insurers.⁶⁴ It registers only names, birth dates, places of birth, occupations and, in three-digit coded form, any medical and selected other factors that could affect insurability.⁶⁵ While the U.S.A. Office of Technology Assessment claims that the MIB database has

⁶¹ Select Committee on Company Law, *supra* note 44 at 238; NIH/DOE report, *supra* note 39 at 16.

⁶² Select Committee on Company Law, *ibid.*

⁶³ NIH/DOE report, *supra* note 39 at 16.

⁶⁴ J.A. Lowden, "Certificates of Confidentiality" Letter to the Editor (1996) 58 Am. J. Hum. Genet. 436 at 437. *Contra*: N.E. Kass, "Participation in Pedigree Studies and the Risk of Impeded Access to Health Insurance" (1993) 15:5 Int. Rev. Biol. 7.

⁶⁵ Select Committee on Company Law, *supra* note 44 at 238.

information about genetic diseases,⁶⁶ Lowden specifies that these genetic diseases are not clearly identified. Huntington's disease, for example, is classified "a disorder of the nervous system." Sickle cell, thalassemia, and iron deficiency anemia are all classified as "anemia."⁶⁷

The MIB keeps its records for a maximum of seven years.⁶⁸ It holds and communicates information on a considerable number of people and has grown considerably in recent years. In the 1960s, ten to fifteen million requests for information were processed every year by the MIB. In 1980, it held information on eleven million life insurance applicants.⁶⁹ This number has increased to as high as fifteen million in the 1990s.⁷⁰

Due to the geographic scope of MIB, it is highly probable that reporting companies use several different standards in reaching conclusions about the health of applicants. The MIB has tried to alleviate the problem of adverse decisions due to erroneous information by stipulating that information received from the MIB should serve "only as an alert to the member, which must through other sources gather additional information to substantiate an unfavourable underwriting decision."⁷¹ It is unclear, however, that this policy can be enforced.⁷² Lowden reports that MIB members are audited regularly by MIB underwriting specialists, who decide whether appropriate rules are being followed. If not, the result is loss of privileges.⁷³ It would be interesting to investigate whether Canada's *Personal Information Protection and Electronic Documents Act*⁷⁴ will have an impact on the practice of the MIB. A discussion of the potential impact exceeds the scope of this paper.

4. Medical Testing

For many life insurance contracts, people are submitted to some health tests. Standard tests used for underwriting purposes are tests aimed at detecting cotinine in a person's saliva, which is an indicator of smoking, and HIV/AIDS tests. For men, underwriting now often includes a test to determine their risk to develop prostate cancer.⁷⁵

⁶⁶ NIH/DOE report, *supra* note 39 at 16.

⁶⁷ Lowden, *supra* note 64.

⁶⁸ Select Committee on Company Law, *supra* note 44 at 238.

⁶⁹ Québec, Commission des droits de la personne, *Échange de renseignements entre compagnies d'assurance-vie et violation de la vie privée*, Résolution COM-93-9.2.11 (11 janvier 1980) at 1.

⁷⁰ NIH/DOE report, *supra* note 39 at 16.

⁷¹ Stengel & Brown, *supra* note 45 at 110; Select Committee on Company Law, *supra* note 44 at 238.

⁷² NIH/DOE report, *supra* note 39 at 16.

⁷³ Personal communication.

⁷⁴ S.C. 2000, c. 5.

⁷⁵ It is interesting to point out that a recent study conducted for the U.S. Preventive

Genetic testing could be added to the various forms of medical tests insurance applicants are submitted to. Insurers could request testing for genetic disorders before offering insurance contracts. This could become part of the application procedure, like other medical tests already used in underwriting.⁷⁶

VI. *The Concept of Utmost Good Faith*

The concept of *uberrima fides*, or utmost good faith, is a crucial characteristic of insurance and merits some explanation.⁷⁷ The principle of utmost good faith in insurance stems from the marine origin of the contract.⁷⁸ In the early days of insurance, and in particular in the context of risky maritime expeditions, it was not only difficult to determine the types of risks to which the other contractor might be exposed, it was even harder, according to Brown and Menezes, to investigate claims.⁷⁹ Because of this difficulty, it was crucial that the contractual parties could rely on the good faith of the other. Although it was hard to verify the veracity of a claim, at least the severe penalty of not respecting this good faith obligation could provide some protection against misuse of the contract. With the development of other means of control and risk assessment, the stringency of the rules of disclosure may have softened somewhat. A maritime insurer then clearly did not have the same power as a life insurer today to investigate what happened. But the history explains the importance attached to the duty of full disclosure.

Services Task Force concluded, after a detailed analysis of the available evidence on prostate cancer screening, that prostate cancer screening can create significant harms without clear indication of benefit (see R. Harris & K.N. Lohr, "Screening for Prostate Cancer: An Update of the Evidence for the US Preventive Services Task Force" (2002) 137:11 *Annals of Internal Medicine* 917). The study indicates that screening does not significantly decrease mortality and may create considerable anxiety, including anxiety based on false-positive results, in the absence of clear benefit from treatment. Although it is not strictly speaking a genetic test, the use of this form of screening by insurance companies raises similar issues about the appropriateness of insurers' use of preliminary health risk information or screening techniques that indicate significant risks and that may even not yet been sufficiently validated. See *infra* for a discussion of this issue in the context of genetic research.

⁷⁶ H. Ostrer *et al.*, "Insurance and Genetic Testing: Where Are We Now?" (1993) 52:3 *Am. J. Hum. Genet.* 565 at 568.

⁷⁷ Brown & Menezes, *supra* note 17 at 1-3; Norwood & Weir, *supra* note 18 at 70, 297; Baer & Rendall, *supra* note 17 at 342; M. Otlowski, *Implications of Genetic Testing for Australian Insurance Law and Practice*, Occasional Paper No.1 (Tasmania: Centre for Law and Genetics, 2001) at 13-14.

⁷⁸ Lluelles, *supra* note 28 at 33 ; R. Moreau, "La plus entière bonne foi" (1993) 60 *Assurances* 577 at 580; Guay, Knoppers & Panisset, *supra* note 2 at 204. The principle was established in *Carter v. Boehm* (1766), 97 E.R. 1162 (K.B.).

⁷⁹ Brown & Menezes, *supra* note 17 at 5-1.

The requirement of utmost good faith can be explained, to some extent, by subscription to a system of risk pooling.⁸⁰ People who enter an insurance contract agree to pay a premium based on their relative risk. Each individual counts on the fact that all others are playing the game according to the same rules and that those who are put in the same pool are exposed to equivalent risk. The exchange of information is a crucial aspect of the insurance contract, as it is on this basis that the price of the contract, *i.e.* the premium to be paid, is determined. Full disclosure, connected to the idea of utmost good faith, is required to obviate information asymmetry, *i.e.* a situation whereby one party has more information relevant to the contract than the other. This would not only make other insured in the same pool pay more than they should, it could, according to insurance experts, even lead to the destabilization of the insurance industry as a result of adverse selection. I will discuss this notion further.

Interestingly, Tom Sorell ponders whether the “knowledge asymmetry” that is mentioned in support for access to genetic information for insurers might not in a way compensate for the asymmetry of knowledge and power created by the financial strength and sophistication of the insurance industry.⁸¹ This might to some extent rectify the contractual imbalance between the two parties. Although this is an interesting theoretical argument, it is clearly not accepted by current insurance law as excusing the insured from the duty of full disclosure.

The requirement of utmost good faith implies that applicants have an obligation to disclose all information that is within their knowledge and relevant to the determination of the nature and extent of the risk.⁸² As I will discuss further in more detail in the context of Canadian law, this means that insurance applicants have to put themselves in the position of a reasonably prudent insurer and try to imagine what he or she would want to know in order to determine the premium to be paid. Insurers, too, are bound by this obligation. They cannot, for example, in bad faith receive payments, waiting to annul the contract on the basis of lack of disclosure once a claim is made.⁸³ They also have to collaborate in good faith in paying out coverage when a reasonable claim is made.

A recent Supreme Court case confirmed the importance attached to the good faith obligation in insurance. In *Whiten v. Pilot Insurance Co.*,⁸⁴ the

⁸⁰ Lluelles, *supra* note 28 at 32; Guay, Knoppers & Panisset, *supra* note 2 at 204.

⁸¹ T. Sorell, “Freedom Within Limits. Underwriting and Ethics” in T. Sorell, ed., *Health Care Ethics and Insurance* (London: Routledge, 1998) 54 at 67.

⁸² Brown & Menezes, *supra* note 17 at 5-2. See also Norwood & Weir, *supra* note 18 at 70. This obligation is recognized by the legislation of all Canadian provinces, including Québec, which will be analyzed further.

⁸³ Brown & Menezes, *ibid.* at 1-3.

⁸⁴ [2002] 1 S.C.R. 595.

Canadian Supreme Court reinstated a \$1 million award in punitive damages rendered by a jury against an insurance company that had been unduly and unreasonably confrontational in refusing to pay a claim. The behavior of the company attracted punitive damages to the extent that it was deemed exceptionally reprehensible. Behavior falling below this threshold will not attract significant awards in punitive damages.

The circumstances in which punitive damages can be awarded was recently specified in *Ferme Gérald Laplante & Fils Ltée v. Grenville Patron Mutual Fire Insurance Co.*⁸⁵ In this case, the Ontario Court of Appeal indicated that punitive damages should be imposed only exceptionally. They should, according to the Court, be used with restraint and be preserved for those circumstances where misconduct was “malicious,” “oppressive,” “high-handed” or “offensive to the court’s sense of decency.” The Court in this case did not consider it appropriate to impose punitive damages on the insurer, but its wording suggests that punitive damages are more likely to be a remedy against the insurer than against the insured. It is therefore less likely that punitive damages would be imposed for not disclosing a risk factor in bad faith. Charron JA’s words are clearly focusing on the insurer:

The implied obligation to act in good faith has been extended beyond mutual disclosure requirements in relation to the nature of the risk being undertaken. In particular, the courts have recognized that the insured, having suffered a loss, will frequently be in a vulnerable position and largely dependent upon the insurer to provide relief against the financial pressure occasioned by the loss underlying the claim. Hence, the obligation to act in utmost good faith requires an insurer to act promptly and fairly at every step of the claims process.⁸⁶

Good faith in the context of life insurance does not mean that those insured are obliged to divulge all medical information obtained *after* the contract is concluded. People may undergo various medical procedures and tests, including genetic tests, *after* signing a life insurance contract, without declaring the results to their insurers. The focus of life insurance contracts is the risk as calculated when the contracts are concluded. If applicants declare all relevant medical facts known at the time, the requirement of good faith is respected. That said, when problems arise, applicants must collaborate in utmost good faith with their insurers in establishing how diseases have developed or accidents have occurred.⁸⁷

⁸⁵ (2002), 61 O.R. (3d) 481 (Ont.C.A.).

⁸⁶ *Ibid.* at 503-504.

⁸⁷ See further below.

VII. What are the Reasons for Using Genetic Information and Genetic Testing for Insurance Purposes and what are the Concerns?

It could be argued that genetic technology, as other medical technology, allows insurers to determine more precisely the risk status of individuals and to set premiums accordingly. In a way, genetics testing focuses very much on the assessment of risk for illness and premature death. While most other medical technologies are used for diagnostic purposes, genetic technology looks at the future. Except for some forms of diagnostic genetic testing, its value lies not in saying something conclusively about the present, but in helping to predict what is more or less likely to happen with someone's health situation. Like insurance, it offers help in gaining control over uncertainty. It could therefore easily be integrated in medical underwriting. In addition to offering a justification for the use of genetic test information known by applicants or available in medical files, this comparison could be invoked to support the use of genetic testing as an underwriting tool. The fact that genetics and insurance are in a way such a good fit lies behind the two reasons invoked to defend the idea that insurers should be able to use genetic information.

A. Adverse Selection

The first reason is a practical one: it relates to the need for insurers to determine premiums according to risk, in order to avoid adverse selection. Insurers want to prevent applicants from hiding crucial risk information and obtaining coverage that is not commensurate to their risk. The second reason is related to the nature of insurance. It has to do with the expectation of those participating in the insurance scheme: people expect to pay according to their risk status.⁸⁸ I will discuss this argument briefly further, looking at the concept of solidarity in the context of insurance.⁸⁹ I want to focus here on the practical reason why insurers are interested in using genetic information and what we should be concerned about with regard to providing access to genetic test results or allowing insurers to impose testing.

So far, insurers have been reluctant to admit that they want to go as far as to conduct genetic testing for underwriting purposes. Different reasons likely underlie this reluctance: it would be badly received by the public if insurers indicated that they would start imposing genetic testing. At any rate, genetic testing is not yet sufficiently developed for it to be financially interesting as an underwriting tool. Until very recently it was still rather

⁸⁸ See "Selective Justice", *supra* note 2 at 384-85; "Use of Genetic information" *supra* note 35 at 92; K.A. Clifford & R.P. Iuculano, "AIDS and Insurance: The Rationale for AIDS-related Testing" (1987) 100 Harv. L. Rev. 1806 at 1807.

⁸⁹ See section 7 below.

expensive, and it did not yet yield sufficient information to be cost effective.⁹⁰ This is why the debate has so far focused mostly on whether insurers should be allowed to have access to genetic test results available in medical or research files, and whether applicants have an obligation to disclose that they have participated in genetic research.

The argument that insurers need access to this form of genetic information is based on the fear for adverse selection.⁹¹ Adverse selection occurs when people who are at higher risk of premature death or disability, have either an increased tendency to apply for insurance coverage, or a tendency to buy more 'luxurious' insurance coverage.⁹² Genetics could lead to adverse selection when people who learn from a genetic test result that they are at higher risk start applying for insurance or increase their coverage, without paying an increased fee in line with their higher risk status.⁹³ This is what insurers are currently worried about: that applicants will get information about their risk status but be allowed to conceal it from their insurer. Insurers will have to pay out more than they expected. They will have to raise premiums to cover unexpected losses. Gradually, prices will go up so significantly that those at lower risk will stop applying for insurance. In the end, according to this model, the industry will collapse.

To level the playing field, insurers argue, they have to know what insurance applicants know with respect to their health risks. In line with existing insurance practice, insurers therefore want to have an opportunity to verify the veracity of an applicant's statement. The most direct source of information for insurers is the applicant's medical and hospital files. Insurers want to be able to verify whether there is any indication in these files about the applicant undergoing genetic testing. They would refuse to pay out coverage to those who have not revealed genetic information that indicates an increased risk.

In theory, requesting tests from applicants goes further than obtaining access to genetic test results already available, since it would provide information that neither the insurer nor the applicant has. In reality,

⁹⁰ One of the most common tests, the BRCA1&2 test offered by Myriad Laboratories, for example, still costs U.S. \$ 2,760.

⁹¹ For a discussion of the issues surrounding adverse selection, see T. Lemmens, *Genetic Information and Insurance: A Contextual Analysis of Legal and Regulatory Means of Promoting Just Distributions* (D.C.L. Thesis, McGill University 2002) [unpublished] at 180-96.

⁹² Angus S. Macdonald, "Human Genetics and Insurance Issues" in I. Torrance, ed., *Bio-ethics for the New Millennium* (Edinburgh: St. Andrew Press, 2000) 25 at 27.

⁹³ See the discussion in Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report 96, vol. 2 (Sydney: Southwood Press, 2003) at 679-682.

imposing genetic testing as a precondition for insurance is the next logical step. Indeed, if no regulation on genetic testing is imposed, it could be offered commercially outside established health care institutions, even on an anonymous basis. Anonymous mail-in systems already exist to test for HIV/AIDS. Why would it be different for genetic testing, a potentially much more significant market? Private laboratories are already advertising for some forms of mail ordered DNA testing, be it to test whether a partner has been faithful, whether children have engaged in premarital sex, or to determine through genetic testing one's ethnic origin.⁹⁴ Marketing for other, more serious genetic tests, is likely to follow. People who think that they are at risk could thus send in a DNA sample and be informed of their risk status without leaving a trace about the fact that they underwent testing. When they test positive for a high-risk genetic condition, they could buy additional insurance without offering any opportunity to the insurer to know about it.

There is, however, a reason to be more concerned and therefore stricter about insurers' ability to impose genetic testing as a precondition for insurance. As I pointed out, the insurance context is hardly the most appropriate one in which to learn about diseases that are (or might become) seriously debilitating. In the context of genetic testing, it is always stressed that people should not be pushed to learn about their risk status and that they even have a 'right not to know' their genetic predisposition or susceptibility to disease.⁹⁵ Graeme Laurie qualifies this right as a component of the right to privacy, precisely because the choice whether or not to learn about one's health risks is a very intimate, personal matter.⁹⁶ In Europe, this right not to be informed is explicitly recognized in human

⁹⁴ Some laboratories do indeed advertise on the WWW for testing of cloths and sheets to see whether there is any 'foreign DNA' to be found. See e.g. Paragon Genetics, online: <<http://www.paragondna.com/index.htm>>; Quest Genetics DNA Lab, online: <<http://paternitytestingassociates.com/index.html>>; DNA Laboratories Corp., online: <https://host33.ipowerweb.com/~genetic/geneticstest.com_infidelity.htm>.

⁹⁵ See Roscam-Abbing, *supra* note 37 at 144; S.M. Suter, "Whose Genes Are These Anyway? Familial Conflicts over Access to Genetic Information" (1993) 91 Mich. L. Rev. 1854 at 1893; N. Park & B. Dickens, "Legal and Ethical Issues in Genetic Prediction for Breast, Ovarian and Colon Cancer Susceptibility" in K.M. Taylor & D. De Petrillo, eds., *Critical Choices: Ethical, Legal and Sociobehavioural Implications of Heritable Breast, Ovarian and Colon Cancer: Background Paper for the International Research and Policy Symposium* (Toronto, 1995) at 70; Privacy Commissioner of Canada, *Genetic Testing and Privacy* (Ottawa: Supply and Services, 1992) at 30.

⁹⁶ G.T. Laurie, "In Defense of Ignorance: Genetic Information and the Right Not to Know" (1999) 6 Eur. J. Health L. 119; *Id.* "Protecting and Promoting Privacy in an Uncertain World: Further Defences of Ignorance and the Right Not to Know." (2000) 7 Eur. J. Health L. 185. For a general discussion of privacy and genetics, see *Id.*, *Genetic Privacy: A Challenge to Medico-Legal Norms* (Cambridge: Cambridge University Press, 2002) at 86-181.

rights law, and directly connected to the right to be informed about personal health information. The European Convention on Human Rights and Biomedicine states in article 10(2) that “[e]veryone is entitled to know any information collected about his or her health.” And it adds to this that “the wishes of individuals not to be so informed shall be observed.”⁹⁷

It seems inappropriate then, to allow pressure to be created in the context of a private commercial contract. Appropriate counselling would probably be unavailable. Allowing private, commercial entities such as insurers to use genetic tests as a tool for differentiation could cause stigmatization, exacerbating social pressures on those affected by genetic disorders.⁹⁸ It removes genetics from the medical context. It gives insurers considerable power, albeit indirect, over an intimate medical decision. The collective and personal costs of allowing genetic fishing expeditions should be weighed carefully against economic risks for the insurance business. Tax fraud by some citizens justifies some government control over the financial affairs of all, but it does not justify unlimited intrusions on individual privacy. The same principle should surely apply to insurance.

Particular concerns also exist when it comes to allowing insurance companies to have access to genetic test information that has become available in the context of research. Much of genetic testing currently takes place in the context of research. Predictive genetic testing for hereditary breast cancer through BRCA1&2 testing, for example, still takes place in the context of long-term research in many academic institutions. Insurers are thus interested in obtaining access to these research results and would not want to see a clear separation between clinical files and research files. As I have pointed out earlier, the Supreme Court’s position on access to medical and hospital files is that there is no limit as to scope and time. People can waive their right to privacy, and insurers can obtain access to research files.

A hypothetical scenario makes it clear how problematic the consequences of such access can be. Let us presume that Josephine T. has seen two members of her family die of a sudden heart failure. Medical experts diagnosed these deaths as probable cases of hypertropic cardiomyopathy or “sudden death” syndrome. The medical experts contact Josephine T. and other family members to participate in a study aimed at identifying the genetic components of the disease. Since these events have made her more aware of the devastating this disease can cause, she is willing to contribute to a better understanding of the disease. She accepts to participate with her family members in this study, which is designed by

⁹⁷ 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, 4 April 1997, E.T.S. No. 164.

⁹⁸ Privacy Commissioner of Canada, *supra* note 95 at 34, recommendation 5(1).

clinical researchers who are also their treating physicians. She knows herself to be a particularly anxious person and she therefore explicitly states that she does not want to be informed if they find a genetic mutation linked to high-risk status. After careful analysis of the DNA of various people who either suffered from, or have family members who suffered from hypertrophic cardiomyopathy, researchers come up with a putative link between the disease and a genetic mutation. They have kept the results of testing on individuals in separate 'genetic research files' and will in the future inform those who consented to disclosure. At this stage, they are still validating the research results. In the meantime, however, Josephine T. decides to apply for life insurance, since she has given birth to a child and feels the need to create some financial stability. The insurance company asks her to sign a waiver of confidentiality to obtain access to all medical and hospital files, which she does. From her genetic file, the medical officers of the insurance company find out that she has a genetic mutation that is tentatively linked to a high-risk condition and decide to refuse coverage. They inform her of the reason. A commercial contractual party has thereby informed her directly of a risk status that she explicitly asked her researcher-clinicians not to divulge to her. This seems inappropriate.

Genetic testing will rarely reveal the type of 'catastrophic' information that comes with a positive test result for the Huntington's gene or hypertrophic cardiomyopathy. Some may therefore be inclined to diminish the importance of the concerns related to genetic testing for non-medical reasons. Against those who would trivialize this concern, one can invoke two arguments. First, risk appreciation is a very personal issue. Some may find it desirable to have information about their genetic risk status for a specific disease and may be able to cope with this information. Others may be seriously troubled by it, and would prefer not to be informed. As a matter of social policy, it seems highly desirable to take into consideration the variability of people's risk perception. Second, regulation and law show their highest value when they are committed to the protection of the weakest. Legal rules often deal with exceptional circumstances. Even if relatively few people will be seriously harmed when insurers can require genetic testing, it is perfectly justifiable to discuss the potential development of legal limits to protect them.

The same concern about inappropriate pressure lies behind the legislative initiatives of countries prohibiting applicants to submit genetic test results, as discussed earlier. 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 insurable."⁹⁹

⁹⁹ Ostrer *et al.*, *supra* note 76 at 570.

As mentioned elsewhere, some Canadian insurers have indeed told applicants with family histories of Huntington's disease that they would have to be tested before getting insurance.¹⁰⁰ Nevertheless, those who previously would have been denied insurance or had to pay very high premiums can now get it by proving that they are not at risk.¹⁰¹ 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.

Commentators have also expressed concern, though, about granting insurers the right to access genetic information stored in medical and hospital files. It could discourage people from being tested.¹⁰² Getting and using the results of genetic tests on family members would infringe their privacy and violate their "right not to be informed." Those denied coverage could be informed that they are at risk for disabling diseases without ever having been aware that these run in their family.

B. Actuarial Fairness

As I indicated, the second reason invoked by insurers to defend their right to obtain access to genetic test information, and to eventually use genetic testing as an underwriting tool is related to a particular concept of fairness. According to insurers, people expect to pay according to their risk status, and it would be unfair to impose a premium on insurance applicants that does not correspond to this status. This is only partially true, however. Underwriting in insurance is limited by considerations of cost-effectiveness. People are only submitted to a limited form of questioning and a limited degree of medical examination. On the basis of this limited information, people are classified in larger risk groups. Within these groups, individual differences with respect to risk profile certainly exist. The fact that most people of the same age and gender pay the same premiums tells us very much about the large categories in which people are classified.

There is clearly some form of solidarity and mutual support in the

¹⁰⁰ See *ibid.*

¹⁰¹ M.E. Brom, "Insurers and Genetics: Shopping for that Perfect Pair of Genes" (1991) *Drake L. Rev.* 121 at 136.

¹⁰² See Ostrer *et al.*, *supra* note 76 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) 17:1-2 *Am. J. Hum. Genet.* 109 at 113; J. Miller, "Physician-Patient confidentiality and Familial Access to Genetic Information" (1994) 2 *Health L.J.* 141 at 151.

concept of insurance. Insured people clearly share an interest: they engage in regular payments, on the understanding that those affected by a peril will benefit from compensation. This is made possible through the formation of a pool of insured people among whom the risk is spread. Whether consciously or not, those insured acknowledge that sharing costs and benefits within a larger community decreases risk and promotes stability. A few people will benefit from the contributions of all. For the Nuffield Council on Ethics, the idea of solidarity in insurance is reflected in “the sharing, by the population, as a whole or in broad groups, of benefits and costs.”¹⁰³

This being said, Canadian insurance law does not reflect directly underlying ideals of social support or compassion. The traditional insurance contract as seen through the lens of insurance law seems fundamentally different from a transaction within the public health or social welfare system. The latter transactions are based on the idea of distributive justice. They are intended to protect everyone equally against mishaps (such as disease and unemployment) independent of age, social status, or physical and mental capacities. Insurance contracts are traditionally seen as financial vehicles that people freely invest in with the hope of benefiting from them. They believe that the certainty of compensation has a specific value for which they are willing to pay. Insurance is considered a luxury, for those who want to create some additional financial security. This traditional view still dominates. It reflects the commercial context in which insurance was originally developed.¹⁰⁴

It should be noted, however, that fairly early on in its history, insurance became used as a tool within a larger social support system. In Canada, the first life insurance legislation was enacted in 1865 in what was then the Province of Canada.¹⁰⁵ The title of this act, “An Act to Secure to Wives and Children the Benefit of Assurances on their Husbands and Parents” clearly indicates that this form of insurance fulfilled an important social function. It protected families from being brought to bankruptcy by the death of the breadwinner of the household. At a time when social provisions were largely non-existent, these insurance contracts could fulfill a crucial stabilizing role. It is worth pointing out that many of our state regulated and state provided public support systems have grown out of, or been

¹⁰³ Nuffield Council on Bioethics, *Genetic Screening: Ethical Issues* (London: Nuffield Council on Bioethics, 1993) at 66, cited also by S.A.M. McLean & P. Gannon, “Genetics and Insurance” in Sorell, *supra* note 81 at 88.

¹⁰⁴ Insurance was first introduced in the context of maritime commercial transactions and to cover against commercial losses. See Besson, *supra* note 28 at 3; J.-G. Bergeron, *Les contrats d'assurance: Lignes et entre-lignes*, t. 1 (Sherbrooke: SEM, 1989) at 31.

¹⁰⁵ McDonald, *supra* note 41 at A1-1.

inspired by, private insurance systems, often established by social groups or charities in an attempt to solidify solidarity and spread the risk of mishap among the members of the group.

The business and law of insurance developed over time. Marvin G. Baer and James A. Rendall suggest two causes of the astonishing growth of the insurance industry in the twentieth century.¹⁰⁶ First, insurance is based on actuarial calculations and therefore requires the collection and storage of information about a large number of people. This became possible only with the advent of modern bureaucracies, methods of accumulating and analyzing large masses of data, sophisticated systems of banking, investment management, and so forth.¹⁰⁷ Second, post-war society has been characterized by an increasing desire for security and financial stability. Both individuals and businesses have been trying to stabilize their financial and social status.

Their explanation seems linked to other developments, for example the growing individualization of society. Because people can count less on charity and communal or family solidarity, they feel a greater need to be financially protected. In an interesting way, private insurance, which seems to have inspired the development of several publicly funded insurance plans, is taking its space back in this context. We have become accustomed to the idea of having some form of externally provided financial stability. Now that the state is withdrawing from many of its public commitments in this area, private insurance becomes more popular. The modern shift in values has also led to an increasing focus on the individual and his or her development. Eternal salvation is no longer the primary focus of most people's lives, and individual accomplishments and success have become more important. Avoidance of or even control over unexpected events are more important in such a context.

The further development of the market economy is, in my view, another reason why insurance has increased in importance. In an increasingly powerful financial market system, the societal desire for control and avoidance of uncertainty has been taken up by clever market strategists, who have developed a wide variety of new insurance products. Furthermore, insurance has developed into a sophisticated institution, encompassing a wide variety of services, often connected to other goods and services in society, such as employment, ownership and money lending.

Richard V. Ericson, Aarond Doyle and Dean Barry also refer to the downsizing of the state in—to use a sociologist's term—our “risk society.”¹⁰⁸ Private insurance, according to them, is taking over part of the

¹⁰⁶ Baer & Rendall, *supra* note 17 at 3.

¹⁰⁷ *Ibid.*

¹⁰⁸ R.V. Ericson, A. Doyle & D. Barry, “Introduction” in R.V. Ericson, A. Doyle & D.

role of government in providing security and stability. It is the market-based mechanism that allows people to take risks. They stress that insurance is of crucial support in a society where the drive for technological progress demands risk taking. “The thrust for progress and thirst for profits,” they argue, “ensure a perpetual dance between the taking and taming of risk.”¹⁰⁹ Insurance permits risk taking by offering financial security in case things go wrong. At the same time, it sets boundaries, by indicating what is insurable and what not. But while it responds to a desire for security, it also has to communicate about risks and about the importance of security, thus contributing to its own success. Insurance addresses a particular ‘need’ within this risk society, and contributes at the same time to the perception of risk and the need of protection. Insurance, according to these authors, is one of the crucial institutions involved in the production and distribution of knowledge of risk, not only for its own purposes, but also for use by other societal institutions.

In my view, these developments support the claim that the traditional view of an insurance contract as a purely private agreement between two equal parties no longer really holds. This seems, to some extent, already recognized by developments in law. An insurance contract is now considered in many legal systems as the “standard form contract,” or “contract of adhesion,” whereby one party enters into a pre-existing agreement and accepts the conditions of the contract as they are set out by the other party.¹¹⁰ Legislative interventions primarily aim to protect the weaker party, the insured, and thus recognize inequality in the contractual relation. As Brown and Menezes point out, “much of insurance law has as an objective the protection of customers.”¹¹¹ They suggest that even the disclosure rules, which exist to make sure that uncertainty remains and that insurance applicants cannot hide special knowledge about their risk status, are aimed at protecting consumers. It prevents the insured from being harmed by fraudulent misrepresentations through which a few applicants could impose an excessive burden on others.

It can further be argued that at least some forms of insurance have acquired the status of social goods that should be accessible as widely as possible. In addition to the overall growing importance of insurance as a provider of security, some forms of insurance have become so important that not having access to them seriously limits a person’s participation in society. Life insurance contracts are often required to obtain mortgages, start businesses, or even buy cars. As pointed out, private health insurance

Barry, eds., *Insurance As Governance* (Toronto: University of Toronto Press, 2003) 3, at 7-8.

¹⁰⁹ *Ibid.* at 8.

¹¹⁰ D. Lluellas, *supra* note 28 at 34.

¹¹¹ Brown & Menezes, *supra* note 17 at 1-5.

is also becoming increasingly important in the context of diminishing governmental support for health care.¹¹²

Economic considerations have so far imposed certain restraints on insurance underwriting. While some people are excluded from coverage, most people do obtain standard coverage. The classification in large risk groups remains standard practice, and keeps resulting in some form of solidarity. The insurance market is at this stage not significantly contributing to the exclusion and stigmatization of those who are genetically at risk for premature death or disability, except for those families affected by rare conditions such as Huntington's disease. But will this remain so? If cost constraints are the main reason for not conducting more detailed underwriting, a lowering of the cost of genetic tests will likely spur the interest of some companies. If genetic chip technology is further developed, allowing for the simultaneous testing for a variety of conditions, computer programs could be developed to determine more precisely an individual's increased or decreased risk. Insurers could start offering very individualized insurance contracts, attuned more precisely to an individual's genetic profile. This could fundamentally alter insurance practice, based on pooling people in large risk groups, and undermine the limited distributive and social role that insurance is currently playing. It could be argued that this development, linked to the social role of private insurance, would warrant tighter regulatory control.

It is unlikely that insurers will require applicants to undergo testing with gene chip technology overnight. The technology is not at that level yet. Moreover, insurers will probably take a wait-and-see approach to this technology, for the same reason that they took this approach to more basic forms of genetic testing: it is not good for public relations to be the first insurance company to introduce new intrusive testing.

More likely is the scenario that this technology which is tested out in the research setting, will yield some promising, yet unconfirmed clinical information. Some insurers could be tempted to gain access to these test results and start using some of the test results in their underwriting process, or refuse to pay out coverage on the ground that applicants had a duty to disclose test results. It is precisely in this context that the following analysis will be important. It demonstrates how judges have shown some flexibility in applying strict rules in insurance law related to the good faith obligations of the parties and the related duties to disclose.

¹¹² For a more detailed discussion on this topic, see "Selective Justice," *supra* note 2 at 385-393, and references there.

VIII. *Canadian Insurance Law and Genetic Testing*

The main characteristics of life insurance, discussed above, are clearly reflected in Canadian insurance law. Although a limited discussion of the statutory provisions related to life insurance will necessarily repeat some of the issues raised above, it is important to set out Canadian law in detail, in order to clarify to what extent potential regulatory options would affect current insurance law. One of the important issues, for example, is whether current insurance laws require the disclosure of the results of genetic tests by applicants, and whether insurance companies can request that applicants undergo genetic testing as part of the underwriting process.

The legislative and regulatory power over insurance is divided between the federal and provincial governments.¹¹³ Those aspects of insurance that are relevant to this analysis fall under provincial jurisdiction over property and civil rights, pursuant to 92(13) of the *Constitution Act, 1867*.¹¹⁴ Provincial and territorial governments¹¹⁵ have exclusive jurisdiction with respect to the form and content of insurance policies (such as disclosure, misrepresentation, entry into force, third party rights and subrogation), agent and broker licensing and conduct, along with marketing and business practices, even for businesses that are extra-provincial in scope.¹¹⁶ Both federal and provincial governments may create insurance companies, but only the provinces may regulate the contractual and business aspects of insurance. Companies created under federal law are bound to respect those rules.¹¹⁷

Common law provinces recognized early the importance of uniformity in legislation and collaborated, in the 1920's, on the design of uniform provisions for insurance.¹¹⁸ In 1921, a draft of a Uniform Life Insurance Act was presented by the Association of Superintendents of Insurance of the Provinces (as the Canadian Council of Insurance Regulators was then called),¹¹⁹ the Canadian Commissioners on Uniform Legislation, and the Canadian Life Insurance Association.¹²⁰ In subsequent years, most

¹¹³ Norwood & Weir, *supra* note 18 at 4.

¹¹⁴ U.K., 30 & 31 Victoria, c.3. (U.K.) (Previously the *British North America Act*). See *Citizens' Insurance Company of Canada v. Parsons* (1881), 7 App. Cas. 96 (P.C.); *Alberta (A.G.) v. Canada (A.G.)*, [1916] A.C. 588 (P.C.); *Canadian Indemnity Company v. British-Columbia (A.G.)*, [1977] 2 S.C.R. 504 [*Canadian Indemnity Co.*].

¹¹⁵ For the sake of clarity "provinces" hereinafter is understood to include the three Canadian territories.

¹¹⁶ For a more detailed discussion of the division of powers, see Norwood & Weir, *supra* note 18 at 4; and Brown & Menezes, *supra* note 17 at 1-9 - 1-12.

¹¹⁷ *Canadian Indemnity Co.*, *supra* note 114 at 519.

¹¹⁸ Norwood & Weir, *supra* note 18 at 20.

¹¹⁹ It was renamed in 1988. See McDonald, *supra* note 41 at C1-1.

¹²⁰ *Ibid.*

common law provinces integrated the Uniform Life Insurance Act into their provincial Insurance Acts, while Newfoundland issued a separate act for life insurance.¹²¹ There is also a Uniform Accident and Sickness Policy Act, which will not be discussed here.¹²² It is common practice to refer to these provisions together as the *Uniform Insurance Act*. Although the uniformity is not absolute and there are minor discrepancies between provincial and territorial statutes, the most important statutory provisions are identical, particularly those bearing on life insurance. I will therefore discuss the statutes in general, and only indicate specific differences where needed. Since the *Uniform Insurance Act* does not exist as enacted legislation, I will primarily refer to the *Ontario Insurance Act* as the reference statute.¹²³ Québec did not join the other provinces in their effort to obtain a uniform legislation.¹²⁴ Still, the provisions of the *Civil Code* are substantially similar to those of the *Uniform Insurance Act*.¹²⁵ I will discuss some of the few substantial differences between the *Uniform Insurance Act* and the *Civil Code* below.

Due to the inter-provincial scope of insurance, inter-provincial co-operation would be important to regulate efficiently the use of genetic information by insurance companies in Canada. Inter-provincial uniformity would help to prevent *forum shopping* by insurance companies wanting to avoid stringent rules in one province. In life insurance, concluding the contract formally in a province could be sufficient to make the law of that province apply. Insurers submitted to stringent prohibitions on the use of genetic testing in one province could be confronted with competitors of a neighboring province offering lower premiums to those applicants from outside the province who are willing to undergo genetic testing. Insurance companies located in a province with strict regulation could receive a disproportionate number of applicants at high risk. A more detailed discussion of the need for inter-provincial or perhaps even international co-operation exceeds the scope of this study, but it certainly deserves further attention.

A. *Duty of Disclosure: General Principles*

Insurance, as discussed earlier, is very much based on risk assessment, and information on personal health risks is to a large degree within the control of insurance applicants.¹²⁶ For that reason, applicants for insurance

¹²¹ *Ibid.*

¹²² See *ibid.*

¹²³ A useful comparison table of the corresponding provisions of the other provinces can be found in McDonald, *ibid.* at C1-6 - C1-7.

¹²⁴ Norwood & Weir, *supra* note 18 at 20-21.

¹²⁵ Brown & Menezes, *supra* note 17 at 1-11.

¹²⁶ P. Deslauriers, "Le questionnaire d'assurance fait une autre victime: quelques

have a duty to declare all information material to the risk. This duty is stated in both the *Uniform Insurance Act* and the *Civil Code*. The *Uniform Insurance Act* provides the following with respect to life insurance:

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.¹²⁷

The obligation of utmost good faith creates 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.”¹²⁸

According to David Norwood and John Weir, the duty of disclosure does more than obliging those insured to tell the truth in their representations. They also cannot “conceal the truth by remaining silent upon matters which have an important bearing upon the risk.”¹²⁹ Brown and Menezes indicate, however, that an insurer’s failure to ask a question may be an indication to be used as evidence that the insurer did not consider this information important.¹³⁰ I will discuss this issue further, analyzing some cases that deal with this issue. The duty of disclosure extends to those whose life or health is to be insured, even if they are not parties to the contract.

The ‘reasonableness’ requirement embedded in the duty to disclose is seen from the point of view of the insurer. Applicants have to disclose everything a “reasonable insurer” would want to know. In the context of genetics, it could be argued that the strong and public expression of interest by the insurance industry in a particular form of information could help them establish the argument that there is an obligation to disclose. Public statements about their need to know the genetic risk status of individuals could thus inform the determination of the reasonable insurer standard.

Since a life-insurance contract involves an agreement about a premium to cover against unknown risks in the future, 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 obtained after

réflexions suscitées par l’affaire *Ouellette*” (1994) 73 Can. Bar Rev. 57 at 58.

¹²⁷ *A.I.A.*, *supra* note 21, s. 567 (1); *B.C.I.A.*, *supra* note 21, s. 41 (1); *M.I.A.*, *supra* note 21 s. 160 (1); *N.B.I.A.*, *supra* note 21, s. 144 (1); *Life Insurance Act*, R.S.N.L. 1990, c. L-14, s. 14(1) [*N.F.L.I.A.*]; *N.S.I.A.*, *supra* note 21, s. 185(1); *O.I.A.*, *supra* note 17, s. 183(1); *P.E.I.I.A.*, *supra* note 21, s. 131(1); *S.I.A.*, *supra* note 21, s. 145(1); *N.W.I.A.*, *supra* note 21, s. 81(1); *N.I.A.*, *supra* note 21, s. 81(1) ; *Y.I.A.*, *supra* note 21, s. 88(1).

¹²⁸ Brown & Menezes, *supra* note 17 at 5-1.

¹²⁹ Norwood & Weir, *supra* note 18 at 297.

¹³⁰ Brown & Menezes, *supra* note 17 at 5-2.

the conclusion of the contract. However, as Otlowski points out, “there may be an obligation to disclose testing has been undertaking [sic], even though the results may not yet be available.”¹³¹

The *Civil Code* provision dealing with the disclosure obligation differs in two important aspects from the provision of the *Uniform Insurance Act*. Article 2408 states:

The client and the insured, if the insurer requires it, is bound to represent all the facts known to him which are likely to materially influence an insurer in the setting of the premium, the appraisal of the risk or the decision to cover it, but he is not bound to represent facts known to the insurer or which from their notoriety he is presumed to know, except in answer to inquiries.¹³²

Following this provision, people who are not parties to the contract, but whose lives are insured, must under Québec law declare all material facts only if the insurer *requires* it explicitly.¹³³ If one family member whose life is insured by another has undergone genetic testing, for example, there is no obligation to divulge the results if the insurer does not ask any question about it. Clients themselves, however, are obliged to report without prompting everything material to the risk, as under common law. The *Civil Code* stipulates that neither applicants nor those insured are obliged to declare facts that insurers know or are presumed to know — except when insurers ask about them. According to the Supreme Court of Canada, insurers are presumed to know information that is available on file¹³⁴ (for example, about a former client).

Another important difference is that the *Civil Code* approaches the duty of disclosure from the point of view of the reasonable applicant. Article 2409 provides that: “[t]he obligation respecting representations is deemed properly met if the representations are such as a normally provident insured would make, if they were made without material concealment and if the facts are substantially as represented.”¹³⁵

Both the *Civil Code* and the *Uniform Insurance Act* provide that 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.¹³⁶ It is worth discussing in greater detail exactly what this means.

¹³¹ *Supra* note 77 at 14.

¹³² Art. 2408 C.C.Q.

¹³³ Bergeron, *supra* note 102 at 222.

¹³⁴ *Coronation Insurance Co. v. Taku Transport Ltd.*, [1991] 3 S.C.R. 622 at 641.

¹³⁵ Art. 2409 C.C.Q.

¹³⁶ *Norwood & Weir*, *supra* note 18 at 299; see also *Brown & Menezes*, *supra* note 17 at 5-2, who do not separate the issues so explicitly.

1. *Facts that are Material to the Risk*

Material information is information relevant to risk appreciation.¹³⁷ It influences insurers in deciding whether to issue policies and in determining the appropriate premium.¹³⁸ The test, as accepted by the Privy Council in *Mutual Life Insurance Co. v. Ontario Metal Products Co.*¹³⁹ is whether, “if the fact concealed had been disclosed, the insurers would have acted differently,”¹⁴⁰ either by changing the premium, declining the coverage, or by inquiring further about the risk. The concept of materiality must be approached in relation to the acceptance of risk,¹⁴¹ and therefore, from the perspective of a reasonable insurer.¹⁴² In *Nova Scotia Marine Insurance Co. v. Stevenson*,¹⁴³ the Supreme Court stated it in the following way: “[t]he test of materiality is the probable effect which the statement might naturally and reasonably be expected to produce on the mind of the underwriter in weighing the risk and considering the premium.”¹⁴⁴ 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? In order for a factor to 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.¹⁴⁵ In *Ontario Metal Products Co.*, the Privy Council dealt with the case of a man who had not declared that he had frequent injections of a tonic referred to as

¹³⁷ *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.).

¹³⁸ *Mutual Life Assurance Company v. Bernier*, [1968] B.R. 595 at 600; *Mutual Life Insurance Co. v. Ontario Metal Products Co.*, [1925] A.C. 344, [1925] 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] D.L.R. 127 [*Ontario Metal Products Co.* (S.C.C.) cited to D.L.R.].

¹³⁹ *Ontario Metal Products Co.*, *ibid.* at 588.

¹⁴⁰ *Ibid.*

¹⁴¹ *Ibid.* at 587.

¹⁴² See Norwood & Weir, *supra* note 18 at 6, 304. With respect to the provisions of the *Québec Civil Code*, it should be noted that even though the expression “reasonable insurer” used in article 2485 of the *Civil Code of Lower Canada* has been replaced in the *Québec Civil Code* by “an insurer”, the majority of authors believe that the objective criteria of the reasonable insurer is still applicable. See D. Luelles, “Déclarations de risque et bénéficiaires d’assurance-vie: de certaines énigmes léguées par le rédacteur du nouveau Code” (1995) 4 *Assurances* 639 at 643; O. Jobin-Laberge & L. Plamondon, “Les assurances et les rentes” in Barreau du Québec & Chambre des notaires du Québec, eds., *La réforme du Code civil* (Québec: Presses de l’Université Laval, 1993) at 1118; P. Deslauriers, *La déclaration précontractuelle de risque en droit québécois* (Cowansville, Qc.: Yvon Blais, 1994) at 52.

¹⁴³ (1894), 23 S.C.R. 137.

¹⁴⁴ *Ibid.* at 141.

“Zambaletti’s,” which was “commonly used as a pick-me-up for persons who are run down.”¹⁴⁶ The Privy Council, following the Supreme Court,¹⁴⁷ accepted that even if the man had declared this to be a treatment for a disease (one of the questions asked for any illnesses), a reasonable insurer would still have agreed to insure him. The risk was therefore not considered to be material. The test for materiality of the risk is thus “objective” in that the courts will use the standard of the reasonable insurer. However, as Brown and Menezes point out, there is also a subjective element to the test.¹⁴⁸ Courts may be persuaded that a particular insurer did not consider information to be material, even if a reasonable insurer would have considered otherwise. The lack of specific questions may be an indication of this, but is not determinative.¹⁴⁹

It is incumbent on insurers to demonstrate that the information to be declared is *relevant* to the risk. A simple affirmation by insurers that specific diseases constitute material circumstances that prohibit them from offering insurance is not enough¹⁵⁰ — even if this affirmation is corroborated by other insurers.¹⁵¹ Unfounded fears and unscientific assumptions cannot be invoked in support of a claim that some fact would have influenced an insurer in concluding a contract. Insurers must prove, through the use of actuarial tables, that there is a reasonable basis for considering a fact material. This could be important in the context of genetics. As long as there is no scientifically valid evidence of a link between a genetic mutation and a disease, insurers would have a hard time proving the materiality of a test.

It can be pointed out that while the common law duty of disclosure in insurance is framed by the perspective of the reasonable insurer, this is not essential to a properly functioning insurance system. Under Québec law, the duty of full representation is met if people declare everything that “a normally provident insured” would declare, and there is no material concealment.¹⁵²

¹⁴⁵ J.-G. Bergeron, “La déclaration du risque et les assurances-vie de non-fumeur” (1988) 48 R. du B. 47 at 50-51.

¹⁴⁶ *Supra* note 138 at 584.

¹⁴⁷ *Ontario Metal Products Co. (S.C.C.)*, *supra* note 138.

¹⁴⁸ *Supra* note 17 at 5-4.

¹⁴⁹ See *ibid.* at 5-2.

¹⁵⁰ 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 that the duty of disclosure only applies to facts that are material to the risk. See *ibid.* at 5-3.

¹⁵¹ *Beaulieu v. Industrielle, cie d’assurance sur la vie*, *supra* note 137 at 224-25.

¹⁵² Art. 2409 C.C.Q.

The Québec provision is not unique. In other jurisdictions, such as Australia and Belgium, the duty of disclosure is also fulfilled if an insurance applicant has disclosed what a reasonable insured would consider material to the risk.¹⁵³ Although in most cases, the difference in approaching materiality from one perspective rather than the other may not be great, the latter approach will excuse an insurance applicant more often when the risk information she possesses is, for example, quite complex, or when the questions asked are vague. I would argue that the perspective of the “reasonable insured” best accommodates the complexities of modern life, in particular, our daily bombardment by new risk information.¹⁵⁴ If the aim of disclosure rules is to avoid information asymmetries, it seems reasonable to approach the duty of disclosure from the perspective of what a reasonable applicant thought relevant. If a reasonable person did not think something had to be declared, it is very likely that this information was not the motivating factor to take insurance anyway. There was, in other words, no real asymmetry in knowledge about risk.

Determining what constitutes a material risk will not always be easy, in particular with respect to preliminary information resulting from, for example, genetic studies. Would there be any reason for an insurance applicant to indicate that he or she had participated in a behavioural genetics study investigating a link between a genetic mutation and a “tendency to engage in high risk behaviour?” What if the research results suggested a link, and revealed that the applicant carried the mutation? In my view, research participation and preliminary research results ought not to be divulged if there is no clear link with increased health risk. There is such an increase in speculative genetic research that participation in genetic research should not be seen as relevant information. Courts should not presume that a reasonable insurer would have wanted that type of information or that a reasonable insured would have thought this to be relevant.

The problem is how to determine the materiality of genetic information for life and disability insurance. Insurers try to establish various degrees of risk. In general, genetic tests can indicate increased chances for developing diseases. These increases seem, in actual insurance practice, to be based on material fact. However, the predictive value of genetic tests varies widely.

2. *Facts Known to the Applicants*

The *Uniform Insurance Act* limits the duty of disclosure to facts that

¹⁵³ T. Gleenan, “Insurance, Genetics and the Law” in Gleenan, Wiesing & Ewald, *supra* note 29, 75 at 77-78. For the Belgian legislation, see *Wet 25 juni 1992 op de landsverzekeringsovereenkomst*, B.S. 20 August 1992, art. 5.

are within the knowledge of the insurance applicant.¹⁵⁵ This limitation seems natural, because we can hardly declare what we do not know.¹⁵⁶ Consequently,

[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.¹⁵⁷

However, inadvertent non-disclosure (for example, when an applicant forgets to disclose material information) remains a vice in the exercise of the duty.¹⁵⁸ Norwood and Weir distinguish from cases where applicants tell the insurer in response to a specific question that they cannot “recall,” suggesting that when applicants declare their doubt, they have fulfilled their duty.¹⁵⁹ I am tempted to agree that a declaration of doubt or uncertainty alerts the insurer to the possibility of other risk factors and makes further investigation possible. This seems in accord with the applicants’ good faith obligation to disclose all known material facts. It also fits within the overall development of insurance law, which seems to expect more effort from insurers in obtaining the necessary underwriting information. That said, in support of this argument, Norwood and Weir rely upon *Cameron v. Coopérants Mutual Life Insurance Society*, a decision overturned on appeal.¹⁶⁰

A distinction can be made between facts and personal opinions or beliefs.¹⁶¹ 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. As Norwood and Weir put it,

[m]atters of their own subjective judgment or matters of their opinion or belief are not “facts” which they must relate to the insurer, so that, in relation to a state of health, they are not called upon to diagnose their own symptoms or to assess their own insurability.¹⁶²

¹⁵⁴ Tony McGleenan seems also supportive of this approach. See *ibid.* at 78.

¹⁵⁵ *O.I.A.*, *supra* note 17, s. 183(1).

¹⁵⁶ Norwood & Weir, *supra* note 18 at 301-302.

¹⁵⁷ *Ibid.* at 301.

¹⁵⁸ See Brown & Menezes, *supra* note 17 at 5-2, n. 4.

¹⁵⁹ Norwood & Weir *supra* note 18 at 306, n. 53.

¹⁶⁰ [1992] I.L.R. para. 1-2882 2025 (N.S.S.C.). See *infra* note 164 and accompanying text.

¹⁶¹ Norwood & Weir, *supra* note 18 at 299.

¹⁶² *Ibid.*

Applicants must, however, relate symptoms if they are aware of them. Even if they did not understand the precise meaning of a particular diagnosis, they at least know that they were in the doctor's office. Similarly, if they underwent a medical test, they have to reveal that to the insurer.

How courts look upon this issue varies substantially. In one case, the court sided with an applicant (for a group mortgage life insurance policy) who knew that he had been treated for ulcerative colitis, but answered in the negative to a question whether he had received any treatment, or consulted any physician, for diseases of the stomach or intestines.¹⁶³ The court declared that although this answer was a misrepresentation material to the risk, it was not within the applicant's knowledge, because the applicant did not know that ulcerative colitis is a disease of the stomach or intestines. But in *Coopérants Mutual Life Insurance Society v. Cameron*,¹⁶⁴ the Nova Scotia Court of Appeal dealt with the case of a couple who together signed an application for mortgage protection, declaring that in the previous five years, they could not recall having been refused insurance. In reality, Mrs. Cameron had been refused group insurance two years earlier. The Court of Appeal ruled that forgetfulness was not a legitimate excuse. The case was one, however, in which the forgetfulness was hard to explain, and in which the court may have had trouble accepting the good faith of the applicant.¹⁶⁵ Other cases, discussed below, indicate that reasonable misunderstandings, even relating to questions regarding material risks, may be excused.

A similar decision was reached by the British Columbia Supreme Court, in the case of a man described by his doctor as a person of limited intelligence, who may have been unable to assess his significant alcohol problem.¹⁶⁶ Although the man drank a substantial amount of Scotch each day, he answered negatively the question whether he had any reason to believe he was suffering from any disorder. As a result, no specific questions relating to substance abuse were asked. The court ruled that he failed to disclose all material facts within his knowledge. It would be interesting to submit this type of case to addiction specialists. Denial is often an integral part of addiction and one of the major reasons why it is so hard to convince people with addictions to accept treatment. If admitting a problem of alcohol dependence is already hard in the closed environment of the family or in a therapy setting, it is clearly less likely to happen when an alcohol dependent person is dealing with a stranger in a

¹⁶³ *Stewart v. Canada Life Assurance Co.* (1999), 14 C.C.L.I. (3d) 178 (Ont. S.C.J.).

¹⁶⁴ [1993] I.L.R. para. 1-2918 2239 (N.S.C.A.), rev'g [1992] I.L.R. 2025 (N.S.S.C.).

¹⁶⁵ *Ibid.* at 2244; McDonald, *supra* note 41 at C5-12.

¹⁶⁶ *Sandhu Estate v. Fidelity Life Insurance Company* (1987), 28 C.C.L.I. 108 (B.C.S.C.).

commercial context. To most of us, drinking a bottle of Scotch a day clearly is a health problem that insurers would want to know about. But is it really within the addicted person's knowledge?

Misrepresentation of a material fact is proven most easily if information in medical files has not been divulged. In that case, it can be surmised that those insured neglected or concealed information.¹⁶⁷ For this reason, insurers often do not request access to medical files until claims are filed. The Supreme Court considers access to medical files an essential element of insurers' right to defend their case when insurance claims focus on the health of the insured.¹⁶⁸

When it comes to genetics, applicants can only be held responsible for failing 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. There is no obligation on the part of applicants to go to great lengths to determine all potential risk factors. In practice, this might discourage people from undergoing genetic tests or seeking genetic counselling to avoid being informed of genetic disorders; 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 to the insurer, if their status as candidates for genetic testing *per se* indicates that they are at higher risk. Similarly, one could argue that if applicants know that a blood-relative has undergone genetic counselling and realize that this means that they are at increased risk, they would have to divulge that 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, and the family member has done so. It must be reiterated, however, that the genetic risk factor must be material. Genetic information is often unclear and easily misunderstood by non-specialists, including family physicians.¹⁶⁹ In that case, how could they inform their patients adequately for insurance purposes? And how could these patients be expected to fully understand its relevance?

As mentioned in the introduction, this issue was specifically raised in *Audet v. Industrielle-Alliance*.¹⁷⁰ Remember that Mr. Tremblay had answered that he had no "physical or mental anomaly," even though he tested positive for myotonic dystrophy. The disease was not significantly expressed and he felt "perfectly healthy." Tremblay experienced only minor symptoms. From the facts, it is clear that the question asked by the

¹⁶⁷ *Audet v. Industrielle-Alliance*, *supra* note 1.

¹⁶⁸ *Frenette*, *supra* note 42.

¹⁶⁹ See D.C. Wertz & J.C. Fletcher, "Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care" (1991) 5:3 *Bioethics* 212.

¹⁷⁰ *Supra* note 1.

insurance company was vague, and could have been interpreted in good faith as referring to a significant current illness. The court nevertheless concluded he had made a fraudulent declaration.

There is a substantial body of case law in tension with the outcome of this case. Some explicitly deal with the interpretation of a vague question related to health conditions and whether an applicant's understanding of it was reasonable. Most of these cases apply the principle of *contra proferentem*,¹⁷¹ which requires ambiguous clauses to be interpreted against those who drafted them.¹⁷² The *contra proferentem* rule was referred to by the Supreme Court of Canada in *Ontario Metal Products Co. v. Mutual Life Insurance Co.*,¹⁷³ where Anglin J. held that since insurers control the preparation of the insurance form, it is equitable to expect that they not leave any room for ambiguity and that if they do, the questions be construed in favour of the insured.

In their discussion of disclosure obligations, Brown and Menezes refer repeatedly to the fact that the context in which insurance takes place has changed,¹⁷⁴ and that more is now expected from insurers in the disclosure procedures. They also have a duty of utmost good faith to obtain necessary information. This explains many of the cases in which courts sided with applicants, finding that insurers should have done a better job formulating questions.

Two cases very similar to *Audet* are *Hallman v. Canada Life Insurance Co.*¹⁷⁵ and *Bank of Nova Scotia v. Canada Life Insurance Co.*¹⁷⁶ In *Hallman*, the Ontario Court of Justice dealt with the case of Mr. Hallman, who saw his insurance claim, based on his wife's death, rejected. About two years before she died from lung cancer, the couple concluded a mortgage life insurance. In the application, Ms. Hallman had answered "no" to the question whether she had received any treatment for, or had been diagnosed with, a "disease of the nervous system." She was, however, suffering from epilepsy at the time and had regular seizures. Fanoj J. ruled that this question was ambiguous and that the insurer could easily have included a specific question about epilepsy. She recognized that "a

¹⁷¹ See the discussion of the application of this principle to insurance cases in McDonald, *supra* note 41 at C3-3 – C3-17.

¹⁷² D.A. Dukelow & B. Nuse, *The Dictionary of Canadian Law* (Toronto: Carswell, 1991) define *contra proferentem* as follows: "In case of ambiguity, a document is interpreted to the detriment of the party who drafted it."

¹⁷³ *Ontario Metal Products Co. (S.C.C.)*, *supra* note 138 at 132.

¹⁷⁴ See *supra* note 17 at 5-5 ("Times have changed since the 1760s"), at 5-1 - 5-2, where reference is made to the impact of these changes on the rules of disclosure. See also *ibid.* at 1-3, 1-8.

¹⁷⁵ (1995), 41 C.C.L.I. (2d) 150 (Ont. C.J. (Gen. Div.)) [*Hallman*].

¹⁷⁶ (1993), 20 C.C.L.I. (2d) 44 (Alta. Q.B.) [*Bank of Nova Scotia*].

medical doctor or an educated lay person would likely classify epilepsy as being within the nervous system,” but that “it would not necessarily be the case for a person as Mrs. Hallman.”¹⁷⁷

In *Bank of Nova Scotia*,¹⁷⁸ Murray J. of the Alberta Court of Queen’s Bench decided in favor of a man who had responded on an insurance application that in the last 24 months, he had not received any treatment for, consulted a physician, or been diagnosed with kidney disease, despite having a 20 year history of passing kidney stones. The court ruled that an insurance applicant could reasonably have considered that passing kidney stones is not the same as having a kidney disease. The court felt, again, that the question could have been clearer.

*Forester Estate v. Life Investors Insurance Co. of America*¹⁷⁹ involved a man who had a stroke three years before applying for mortgage life insurance. He was taking anti-coagulant drugs. When asked whether he had received treatment or had been diagnosed with elevated blood pressure, heart trouble or stroke in the 24 months prior to his application, he answered “no.” Interestingly, the court ruled in favor of the insured. It ruled that the drugs were purely prophylactic and were not to be considered treatment. His blood pressure was rather high, but did not require medication, and he had not been diagnosed with “elevated blood pressure,” although his doctor deemed he had “borderline hypertension.” If the insurance company wanted to know more details, the Saskatchewan Court of Queen’s Bench held, it could have asked specifically whether the applicant suffered strokes in the past.

Audet was different in that the question at issue was very general, covering many different ailments, whereas the questions at issue in these three cases were more specific. However, if we follow the same approach and apply the doctrine of *contra proferentem* to *Audet*, it seems plausible to argue that Mr. Tremblay could reasonably have thought that he did not suffer from any physical or mental anomaly. If taking prophylactic medication after a stroke is not deemed treatment, surely a genetic condition that is not seriously expressed can be understood as not falling under the definition of physical or mental anomaly.

A case that dealt with the interpretation of a much vaguer question is also worth mentioning. In *Bradford v. Cumis Life Insurance Co.*,¹⁸⁰ an applicant for insurance connected to a loan had confirmed that she was “physically able to perform or within a reasonable time to resume” her normal activities of livelihood. The applicant had been suffering for

¹⁷⁷ *Supra* note 175 at 155.

¹⁷⁸ *Supra* note 176.

¹⁷⁹ (1998), 6 C.C.L.I. (3d) 209 (Sask. Q.B.).

¹⁸⁰ (1989) 40 C.C.L.I. 133 (B.C. Co. Ct.).

several years from depression, which prevented her from working as a teacher. The court interpreted the term “physically able” very restrictively as being related to bodily function and ruled in favor of the insurance applicant.

B. Sanction for Failure to Respect the Duty of Disclosure

The law sanctions failures to respect the duty of full disclosure severely. Under the *Uniform Insurance Act*, either failing to disclose or misrepresenting a material fact renders a contract for life or accident and sickness insurance voidable.¹⁸¹ Similarly, article 2410 of the *Civil Code* stipulates that “any misrepresentation or concealment of relevant facts by either the client or the insured nullifies the contract at the instance of the insurer, even in respect of losses not connected with the risks so misrepresented or concealed.”

Even if the *Uniform Insurance Act* does not say so specifically, 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.¹⁸² This principle can be explained by considering the problem in connection with the formation of contracts: if an insurer is informed correctly about the circumstances relevant to risk, it might refuse to issue coverage, or it might only issue coverage for high premiums.¹⁸³

In the case of group insurance, misrepresentation or concealment by one member of the group can be grounds to nullify the contract only if the insurer had requested evidence of insurability. Even then, the contract is affected only as far as this individual is concerned. The *Uniform Insurance Act* provides as follows:

In the case of a contract of group insurance, a failure to disclose or a misrepresentation of such a fact in respect of a person whose life is insured under the contract does not render the contract voidable, but, if evidence of insurability is specifically requested by the insurer, the insurance in respect of that person is voidable by the insurer unless it has been in effect for two years during the lifetime of that person, in which event it is not, in the absence of fraud, voidable.¹⁸⁴

¹⁸¹ *A.I.A.*, *supra* note 21, ss. 567(2), 679(2); *B.C.I.A.*, *supra* note 21, ss. 41(2), 97(2); *M.I.A.*, *supra* note 21, ss. 160(2), 219 (2); *N.B.I.A.*, *supra* note 21, ss. 144(2), 202(2); *N.F.L.I.A.*, *supra* note 127, s. 14(2); *N.F.L.A.S.I.A.*, *supra* note 128, s. 20(2); *N.S.I.A.*, *supra* note 21, ss. 185(2) and 82(2); *O.I.A.*, *supra* note 17, ss. 183(2), 308(2); *P.E.I.I.A.*, *supra* note 21, ss. 131(2), 191(2); *S.I.A.*, *supra* note 21, ss. 145 (2), 242(2); *N.W.I.A.*, *supra* note 21, ss. 81(2), 185(2); *N.I.A.*, *supra* note 21, ss. 131(2), 191(2); *Y.I.A.*, *supra* note 21, ss. 88(2), 192(2).

¹⁸² Norwood & Weir, *supra* note 18 at 298.

¹⁸³ Lluelles, *supra* note 28 at 235.

¹⁸⁴ *A.I.A.*, *supra* note 21, s. 568(3); *B.C.I.A.*, *supra* note 21, s. 42(3); *M.I.A.*, *supra* note 21, s. 161(3); *N.B.I.A.*, *supra* note 21, s. 145(3); *N.F.L.I.A.*, *supra* note 127, s. 15(2);

The *Uniform Insurance Act* provides the same with respect to group sickness and accident insurance.¹⁸⁵ The *Civil Code* applies substantially the same rule with respect to all kinds of group insurance: “In group insurance, misrepresentation or concealment by a participant as to age or risk affects only the insurance of the persons who are the subject of the misrepresentation or concealment.”¹⁸⁶ This principle, applicable both in common law and civil law, is supposed to protect members of a group against the failure of one or several other members to fulfill their duty of full disclosure.

C. *The Incontestability Period*

Under both the *Uniform Insurance Act* and the *Civil Code*, an inadvertent failure to disclose or a misrepresentation of a material fact does not render the contract voidable if more than two years have passed since the conclusion of the contract. This clause is a clear example of how insurance law explicitly softens the duty to disclose for the benefit of the weaker contractual party, *i.e.* the insurance applicant. The incontestability period is nevertheless linked to one of the fundamental aspects of insurance: good faith. Inadvertent disclosure is considered less blameworthy in the context of a contract that relies so much on good faith. 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 even in cases of inadvertent misrepresentation or concealment of material facts. The two-year period is a legal maximum. Insurers can provide by contract a shorter incontestability period but cannot stipulate a longer period.¹⁸⁷ 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.

In the context of the earlier *Audet* case, one could have expected the court to consider more carefully the application of the provisions related to the incontestability period. As already argued, when questions are unclear, the *contra proferentem* rule already allows the court to interpret an unclear clause to the benefit of the insurance applicant. But even if this rule were not applied, for example because the question was not ambiguous enough,

N.S.I.A., *supra* note 21, s. 186(3); *O.I.A.*, *supra* note 17, s. 184(3); *P.E.I.A.*, *supra* note 21, s. 132(3); *S.I.A.* *supra* note 21, s. 146(3); *N.W.I.A.*, *supra* note 21, s. 82(3); *N.I.A.*, *supra* note 21, s. 82(3); *Y.I.A.*, *supra* note 21, s. 89(3).

¹⁸⁵ *A.I.A.*, *ibid.*, s. 679(3), 680(1); *B.C.I.A.*, *ibid.*, s. 97(3); *M.I.A.*, *ibid.*, s. 219(3); *N.B.I.A.*, *ibid.*, s. 202(3); *N.F.A.S.I.A.*, *supra* note 128, s. 20(3), para. 21(1)(b); *N.S.I.A.*, *ibid.*, s. 82(3), para. 83(1)(b); *O.I.A.*, *ibid.*, ss. 308(3), 309(1); *P.E.I.A.*, *ibid.*, s. 191(3); *S.I.A.* *ibid.*, s. 242(3), para. 243(1)(b); *N.W.I.A.*, *ibid.*, s. 185(3), para. 186(1)(b); *N.I.A.*, *ibid.*, s. 185(3), para. 186(1)(b); *Y.I.A.*, *ibid.*, s. 192(3), para. 193(1)(b).

¹⁸⁶ Art. 2423 C.C.Q.

¹⁸⁷ Norwood & Weir, *supra* note 18 at 105; see also Art. 2414 C.C.Q.

it would still seem appropriate, particularly in the context of complex genetic information, to presume good faith on the part of the insurance applicant, unless there is a clear indication to the contrary. Was it really a strong indication of bad faith that Mr. Tremblay denied that he had a ‘physical or mental anomaly’ while knowing that he had this genetic condition? Many would probably agree that the use of the terms ‘physical or mental anomaly’ left room for interpretation.

IX: Conclusion - Genetic Information in Insurance Law: Current Mechanisms, Future Options

Under current insurance law in Canada, nothing prevents insurers from requesting the results of genetic tests obtained by applicants, and from using that information in the underwriting process if the information indicates a higher risk for premature death or disability. Insurers can also request access to medical files and use the results of genetic tests contained in those files, provided that this information clearly indicates a higher risk. Insurers could also require genetic testing as precondition for insurance. Nothing in the law prohibits insurers from doing so. Insurance applicants would, under the traditional view of contractual freedom, be free to accept or reject this pre-condition.

I have argued that the possibility of unlimited use of genetic testing information is a cause for concern. Permitting insurers to request genetic testing or to conduct genetic testing as part of the underwriting process removes genetic testing from the health care context. People could, in the future, be pushed to undergo genetic testing in order to obtain insurance, which runs counter to the idea that people should only undergo genetic testing for clinical reasons. I have also indicated that the use of genetic test results contained in research files seems problematic.

There is no precedent in the *Uniform Insurance Act* for the prohibition of particular medical tests for underwriting purposes. A provision prohibiting the use of genetic information or the imposition of genetic testing could, however, be introduced by provincial legislatures, as has been done in some European countries. It would constitute a break with current insurance law, but that should not be a reason to dismiss it as an option. As Brown and Menezes point out, consumer protection is one of the core underlying values in insurance law. They also point out that disclosure requirements have evolved over time and that insurance practice relies less, these days, on full disclosure of risks by insurance applicants.¹⁸⁸ One could argue that restrictions on underwriting practices in the context of genetics would be another development towards strengthening consumer protection.

¹⁸⁸ See *supra* note 17 and accompanying text.

Although limiting the use of genetic testing and even access to some forms of genetic information for insurance companies seems a reasonable policy option, determining the extent of the limits is challenging. There is a valid concern that if insurers cannot use any form of genetic test results, they will be confronted with adverse selection. In the end, it could eventually undermine the business itself. Much will depend, however, on the type of genetic testing. While there is a reason to be concerned that people with ‘determinant’ genetic information—such as a positive test result for Huntington’s disease—would be tempted to apply for excessive coverage, most genetic information leaves room for interpretation and uncertainty and would not as easily lead to significant adverse selection. Still, many of these forms of genetic test results do provide risk information, and indicate an increased risk that is not fundamentally different from risks indicated by other forms of underwriting. For that reason, I have argued elsewhere that a regulatory review process is needed.¹⁸⁹ A regulatory review of genetic testing would focus on evaluating the scientific validity of the technology, the predictive nature of the genetic test, as well as the potential societal implications of its use. And it would certainly have to look at the potential economic implications of allowing or not allowing insurance companies to have access to the results or to the direct use of the technology. The review would help us to reconcile the economic reality of private life insurance with the societal interest in protecting against inappropriate use of intimate medical information.

Awaiting the establishment of such a regulatory review process, I have showed in this paper that there are some tools in existing insurance law that will allow courts to reduce potential misuse of new forms of genetic information that are not sufficiently validated. Under current insurance law, whether insurance applicants have a duty to disclose the results of genetic tests will depend on the information obtained. Two central questions will drive a legal inquiry: was the information material to the risk? And, second, was it known to the applicant? As pointed out above, it could be argued that preliminary tests undertaken in research that do not establish a strong link between a genetic mutation and an increased risk, are not facts material to risk. Similarly, the fact that an applicant has participated as a volunteer in a genetic study investigating, say, genetic influences on behaviour, is not something that has to be divulged. If, however, the applicant participated in a genetic screening study and received confirmation that she had a newly identified genetic mutation associated with a significant increase in cancer risk, she would have an obligation to declare this material fact.

¹⁸⁹ See “Selective Justice” *supra* note 2 at 411-412; and T. Lemmens, “Genetics and Insurance Discrimination. Comparative Legislative, Regulatory and Policy Developments and Canadian Options” *Health Law Journal* (forthcoming 2003).

It could also be argued that a person informed of a serious familial genetic risk by a family member who had undergone genetic testing has an obligation of utmost good faith to reveal that information to insurers. The result must, however, be material to the risk. A genetic test indicating a high risk of becoming deaf, for example, would not constitute a fact material to the risk for a life insurance contract, since deafness is not a condition that increases someone's risk for premature death.

Applicants who have undergone genetic testing for a condition for which the link between a genetic mutation and the disease is clearly established may have done so for the purposes of research, and may have refused to be informed about the results. In that case, there is obviously no obligation for them to try to obtain that test result before concluding an insurance contract. They do not have to declare what they do not know. But, following some of the decisions mentioned above, they would have an obligation to divulge that they may be at higher risk for premature death or disease if they were selected to participate in the research because of their high risk status (e.g. because of a family history of a genetic condition).

Following *Frenette*,¹⁹⁰ the law in Canada currently does not seem to prevent insurers from accessing research files to the extent that they relate to individual applicants who have waived their right to confidentiality. This is unfortunate. As I argued, there are significant reasons, such as the potential for psychological harm resulting from the commercial use, misinterpretation and involuntary disclosure of highly speculative genetic research information, why access to these results should be limited. It can be hoped for that if the Supreme Court is offered an opportunity to deal with this issue, it will consider these risks when balancing the interest of respecting general contractual waivers of confidentiality against the need for privacy protection. In light of the privacy challenges posed by the further development of genetic technology, it would seem appropriate to refine the *Frenette* ruling, by indicating that a general waiver of confidentiality with respect to medical and hospital records should not extend to research results that are speculative, not yet sufficiently validated and not shared with research subjects. The difficulty will be to determine what kind of research information ought to fall under such a protective regime. Indeed, many forms of accepted genetic testing take place in the research context but are subsequently used in clinical care. This indicates how important it will be to have a clear regulatory review process in place to evaluate and assess the validity and value of genetic testing, and to determine the context in which the information of such tests can be used. Awaiting such review process, a court dealing with this issue could issue interpretative guidelines to determine when research results ought to be

¹⁹⁰ *Supra* note 42.

considered robust enough to constitute information relevant for the purpose of insurance underwriting.

One way of justifying a restrictive interpretation of a waiver of confidentiality would be to use precisely the doctrine that underlies the legal validity of such waiver. Indeed, a waiver of confidentiality is based on the idea of contractual autonomy. If people are fully autonomous contractual agents, they ought to be allowed to waive their right to confidentiality. But in order to speak of truly autonomous exercise of contractual choice, a person has to be adequately informed. I want to suggest here that in light of the uncertainty related to genetics, the unclear status of research files, and the potential lack of understanding among research subjects of what fits under the notion of medical or hospital file, a general waiver of confidentiality should not be seen as a blanket authorization to provide access to research files. The validity of blanket consent forms has already been criticized when it comes to access to health records. For Richard C. Turkington, for example, “the legal sanctioning of general releases or blanket consents for the disclosure of health information” creates a “black hole of confidentiality for private health records.”¹⁹¹ If a general waiver can already be seen as undermining the very notion of *informed* consent when it comes to access to medical records, it surely should be seen as a form of “uninformed consent” for access to research files containing speculative, preliminary genetic information, in particular if research subjects themselves did not want to receive it.¹⁹²

¹⁹¹ R.C. Turkington, “Medical Record Confidentiality Law, Scientific Research, and Data Collection in the Information Age” (1997) 25 J.L.M.E. 113 at 115.

¹⁹² The notion “uninformed consent” comes from Paul M. Schwartz, “The Protection of Privacy in Health Care Reform” (1995) 48 Vand. L. Rev. 295, cited by Turkington, *supra* note 191 at note 22.

