

THINK PAPER

I. GENETIC DISCRIMINATION IN CANADA

A) *What is Genetic Discrimination?*

Genetic discrimination is defined by the Canadian Coalition for Genetic Fairness (CCGF) as follows:

Genetic discrimination occurs when people are treated unfairly because of actual or perceived differences in their genetic information that may cause or increase the risk to develop a disorder or disease.

For example, a health insurer might refuse to give coverage to a woman who has a genetic difference that raises her odds of getting ovarian cancer. Employers also could use genetic information to decide whether to hire, promote or terminate workers.

The fear of discrimination can discourage individuals from making decisions and choices, which may be in their best interest. For example, a person may decide not to have a genetic test for fear of consequences to their career or the loss of insurance for their family, despite knowing that early detection and treatment could improve their health and longevity.

Where an individual has already been diagnosed with a disease or disorder, this condition would be captured by the definition of “disability”. Genetic discrimination and the discussion below will focus on the potential or risk a person has to developing a disease or disorder. The CCGF describes the Canadian system as one that deals with instances of genetic discrimination on an *ex post facto* basis. The current system is arranged to deal with discrimination after it has happened. However, even the *ex post facto* regime may not always be able to provide a remedy to individuals discriminated against on the basis of genetic characteristics. As such, there is strong evidence to support the need for legislative action in this area. Such action would equitably distribute the assumption of additional risk in insurance, giving a competitive advantage to none. As with other consumer goods and services, the additional expense would be passed down to the consumers.

B) *Why is genetic discrimination an important issue?*

The World Health Organization has cautioned that “[g]enetic screening or testing should not be introduced in a country without first having clear and enforceable legislation prohibiting the use of genetic tests for health insurance or the use of genetic information by insurance companies in decisions to offer or deny health insurance, or in setting health insurance rates for individuals or

groups. A similar ethical case can be made for not allowing use of genetic information in underwriting of disability insurance . . .”¹

The concern is that the failure to have legislation in place prohibiting genetic discrimination will lead to a genetic underclass which cannot access insurance at reasonable rates. Presently, Canada does not have this protective legislation. Thus genetic test results can be used in the insurance context. To avoid the risk of increased premiums or denied applications, individuals may choose not undergo genetic testing out of fear of the need to disclose the results. The consideration of genetic information in insurance decisions also fails to account for the many factors that can influence whether a predisposition manifests itself as a disease or condition. For example, just because an individual has a genetic predisposition that may increase the risk of developing a disease, the other influencing factors may prevent the disease or condition from developing.²

This issue is becoming increasingly important as private insurance is being used more often to supplement the health care services that are no longer being offered pursuant to public health care systems. Below, will describe how genetic predispositions can be protected under human rights legislation and the circumstances in which a *bona fide* justification to the discrimination can be raised.

It is important to remember that the hallmark of discrimination law is that protection is afforded to ascribed characteristics. Sex, age, race and other enumerated grounds are outside of the individual’s control. Genetic markers are no different. Individual should not be treated differently on the basis of their genes. Further, there is an increasing amount of research being done that demonstrates the many factors that play a role in the transition from a genetic predisposition to the actual development of symptoms and a condition.

II. LAW

A) Is a genetic predisposition protected as a disability under human rights legislation?

i. Employment law

The issue of genetic characteristics and resulting predispositions have been considered to be a form of disability as an enumerated ground. The leading case defining disability in the human rights context arose out of Quebec.³ The Court addressed the complaints of three individuals who had been fired or turned down for positions on the basis that they tested positive for different medical conditions. Two of the applicants had an anomaly of the spinal column while the other had Crohn’s disease. While the case was not directly about genetic discrimination, the Court accepted a broad definition of the term ‘handicap’ to include these genetic susceptibilities as a protected ground.⁴ The Court reasoned that “[g]iven both the rapid advances in biomedical technology, and more specifically in genetics, as well as the fact that what is a handicap today

¹ Advisory Committee on Health Research, Genomics and World Health: Report of the Advisory Committee on Health Research (Geneva: WHO, 2002) at 158-59.

² For more information on this see Trudo Lemmens, “Selective Justice, Genetic Discrimination and Insurance: Should we single out Genes in our Laws?” 45 McGill L Rev J, 347-412 (2000) beginning at para 107.

³ (*Commission des droits de la personne et des droits de la jeunesse*) v. *Montréal (City)*; *Quebec (Commission des droits de la personne et des droits de la jeunesse)* v. *Boisbriand (City)*, [1999] 1 SCR 381.

⁴ *Ibid* at para 76.

may or may not be one tomorrow, an overly narrow definition would not necessarily serve the purpose of the *Charter* in this regard”.⁵

This case has been cited as authority for the principle that human rights legislation protects individuals from discrimination based on a perceived disability. This is consistent with *J v London Life Insurance Co*, [1999] BCHRTD No. 35. In that case, a man was denied insurance coverage on the basis of a perceived disability as he was at risk of developing HIV. As in that case, the perception that a person is at risk of developing a condition or disease that is genetically linked constitutes a perceived disability and is protected under *Charter* and the Ontario *Human Rights Code*, RSO 1990 c.H.19. Another example of this interpretation is found in *Chen v. Ingenierie Electro-Optique Exfo*, 2009 HRTO 1641 (CanLII), at para 16:

The definition of disability is interpreted in a broad manner and extends to the actual or perceived possibility that an individual has or may develop a disability in the future: *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montreal (City)*, [2000] 1 S.C.R. 665, 2000 SCC 27 (CanLII) [reported 37 C.H.R.R. D/271]. For example, if an employer believes that an employee's condition will interfere with business operations and or profitability and for that reason dismisses an employee, this perception and consequent treatment can give rise to a finding of discrimination on the basis of a disability under the *Code: Boodhram v. 2009158 Ontario Ltd.*, 2005 HRTO 54 (CanLII) [C.H.R.R. Doc. 05-738]. emphasis added)

Thus it is discriminatory to terminate, or refuse to hire an employee on the basis that he or she may develop a disability in the future based on their genetic information. The concern regarding the potential development of a disability in the employment context was canvassed in *Sleegers v Spicer's Bakery of Aylmer Ltd*, 2013 HRTO 174. The Tribunal heard a case alleging that the Applicant was dismissed because of a heart attack and other health-related absences (at para 1). While not genetically linked, the issue of perceived heart condition arose which is analogous to the issue of a genetic predisposition which provides an indication of how the Tribunal might consider an instance of genetic discrimination. In *Sleegers*, the case was dismissed because of a lack of evidence; however it accepted that discrimination on the basis of perceived disability was possible:

There is no evidence before the Tribunal that the applicant did, in fact, have a health issue or a medical condition at the time her employment was terminated that would constitute a disability. It is not clear that she continued to have an unrelated medical condition, about which, the respondent was apparently unaware. There was no evidence that she continued to have a heart condition or that she continued to have medical issues in January/February 2011 arising from her medical treatment. However, **the definition of disability extends to a perceived disability or to the actual or perceived possibility that an individual may develop a disability in the future.** See, for example, *Chen v. Ingenierie Electro-Optique Exfo Inc.* 2009

⁵ *Ibid.*

HRTO 1641 and, *Hinze v. Great Blue Heron Casino*, 2011 HRTO 93. As such, if the respondent's decision to terminate the applicant's employment was, in any way based on her previously having a heart attack and/or because the respondent perceived the applicant had a resulting heart condition or **could develop** a heart condition or had a further medical condition that would affect her ability to attend work and perform her job in the future this would constitute discrimination based on disability (at para 32, emphasis added).

Again, in *McLean v DY 4 Systems*, 2010 HRTO 1107, the Tribunal heard a case where the Applicant was dismissed allegedly because the Respondent perceived she had a disability in the form of inactive Tuberculosis (TB). The Respondent's knowledge that the Applicant may have contracted TB and it was a factor in the decision to terminate the Applicant:

TB can become active at any time. It is not a minor or transitory illness, and it therefore meets the definition of disability for the purposes of the *Code*. Obviously in this case, the applicant was mistaken in thinking that she had contracted any form of tuberculosis. However, a perceived disability can also meet the definition of disability for the purposes of the *Code* . . .

Clearly, decision-makers at all levels of the respondent corporation were also aware that the applicant might have inactive TB at the time the decision was made to fire the applicant. It was not until well after the applicant had been fired that anyone could be sure that she did not have TB at all. Further, the respondent's witnesses were aware that the applicant intended to pursue a Workers' Compensation claim, which indicates that the applicant, at least, thought that her ability to continue regular attendance at work and handle her normal workload was in doubt for health-related reasons (paras 51, 60).

Another example is *Davis v Toronto (City)*, 2011 HRTO 806, at para 1.⁶ The Tribunal heard the case of a firefighter whose conditional offer of employment was revoked when the employer learned that the Applicant had a prior knee injury which resulted in osteoarthritis. The Tribunal concluded:

Having regard to the provisions of the *Code*, the Commission submitted that this is a case of discrimination on the basis of a perceived disability. In this case, there is no disagreement that complainant had end stage osteoarthritis at the time of the events. However, he was completely asymptomatic, without functional limitations. ***The City based its decision not to hire the complainant on the pathology, and not on the actual functional abilities.*** In this sense, ***the complainant did not have a disability, but he was perceived to have one.*** It is also apparent from the evidence that the City was concerned

⁶ Request for reconsideration refused, 2011 HRTO 1095.

that the complainant may become incapacitated at some point in the future.

While there is no case directly on point, these cases support a conclusion that a case could be brought, where an Applicant was discriminated against on the basis of a perceived disability in the form of a genetic marker which displayed the potential to develop a condition or disease.

ii. Insurance law

This issue of genetic discrimination also extends to the context of insurance law. A foundational element of insurance law is disclosure so that the insurance company can assess the risk that it is underwriting. As a result, insurance companies are likely to make the argument that they require the disclosure of genetic predispositions where available because it provides guidance regarding the level of risk associated with insuring the individual.

In *J v London Life Insurance Co*, a man was denied insurance coverage on the basis of a perceived disability as he was at risk of developing HIV. The man's wife was HIV positive so the insurance company insisted that the Applicant undergo testing. The Applicant was found to be HIV-negative, yet he was still denied insurance coverage.

... London Life did not perceive that J. was disabled. ***Rather, London Life perceived that J. was at risk of becoming disabled because of his sexual relations with an HIV-positive person, and consequently denied him coverage.***

There is a distinction between a perception that a person is disabled at the time of application and a perception that a person has a propensity or predisposition to become disabled in the future. This distinction was discussed in *Biggs v. Hudson* (1988), 9 C.H.R.R. D/5391. Biggs considered whether a person is entitled to the protection of the *Human Rights Act* on the basis that the person falls within a group of persons considered to be at a high risk of contracting HIV. The Council said:

Unfortunately, myths and fears about HIV are varied and prevalent. That being so, individuals may be perceived by people outside these groups as being carriers of HIV and would, therefore, transmit the virus to others. (at D/40354)

After an extensive review of the Canadian and American jurisprudence, the Council concluded:

... any person who belongs to groups widely regarded as especially vulnerable to HIV infection but who are not HIV infected or whose HIV status is unknown ("high risk" groups), may be protected under the term "physical disability" in the *Act*. Similarly, any person who associates with persons in the groups described above or those who are seropositive may be protected under the term "physical disability" in the *Act*. Again, subject to any consideration of *bona fide* occupational

requirement as may be applicable, these persons or classes of persons will be protected under ... the *Act* if there is discrimination because of a perception or impression that the person or classes of persons would be a carrier or transmitter of HIV or the commonly used term, AIDS. (at D/40360).

In light of the analysis in *Biggs*, I conclude that the term "physical disability" does prohibit discrimination on the basis of a perceived propensity to become disabled in the future (at para 43-46, emphasis added).

The jurisprudence supports that an individual's genetic characteristics and predispositions will be protected as an enumerated ground of disability because it is interpreted as a "perceived disability". It is also possible that an insurance company could be held liable for failing to insure a person because of a genetic predisposition. However, even if a *prima facie* case of discrimination in either the employment or insurance context could be made out, the justifications found within human rights law, such as the *bona fide* occupational requirement or a reasonable justification must be considered.

B) Genetic discrimination as a bona fide justification or occupational requirement
i. Employment Law

It is well established in human rights law that in some instances, otherwise discriminatory behavior can be justified. The Supreme Court of Canada ruled on *British Columbia (Public Service Employee Relations Commission) v BCGSEU*, [1999] 3 SCR 3 [*Meiorin*] and *British Columbia (Superintendent of Motor Vehicles) v British Columbia (Council of Human Rights)*, [1999] 3 SCR 868 [*Grismer*] are the seminal cases on these justifications.

In *Meiorin*, the Supreme Court of Canada articulated the defence of a *bona fide* occupational requirement. When an employee has established a *prima facie* case of discrimination, the employer must demonstrate that the impugned standard was 1) adopted for a goal or purpose which is rationally connected to the function; 2) adopted in good faith based on the belief that the standard was necessary to fulfill the goal; and 3) that the person cannot be accommodated without facing undue hardship.

This test was applied again in *Grismer* and has become the leading test for *bona fide* and reasonable justification defences (at para 20). In *Grismer*, the Court considered this to be the test to justify a *bona fide* occupational requirement, as well as for a *bona fide* and reasonable justification defence (at para 10). Thus, if an employer can satisfy the criterion above, it can discriminate on the basis of an employee's genetic make-up.

An example of this could be found when, after making an offer of employment, an employer asks questions regarding the applicant's ability to do the essential aspects of the job. There is little guidance regarding the time frame of this inquiry. No doubt, the potential employee is required to consider their ability to perform the essential aspects of the job at the time of the offer. However, it is less clear whether this requires the disclosure of information that may affect the employee's ability to do the job in 5, 10 or 20 years. This creates a dilemma for the would-be employee regarding how much he or she should disclose. Based on the disclosure, the employer is entitled to revoke the offer of employment if it can demonstrate that it is unable to accommodate the employee without suffering from undue hardship.

At present, in some contexts, an employer is allowed to subject an employee to a drug test where the safety of the workplace depends on the sobriety of the employee.⁷ This is justified under the *Meiorin bona fide* occupational requirement test as described above. It is possible that employers could make analogous arguments regarding genetic predispositions being tied somehow to safety requirements. This is further supported by the *Canadian Human Rights Act*, RSC, 1985, c.H-6, s.15(2) provides that safety is one criterion considered in the undue hardship analysis. Thus, if an employer could demonstrate a safety related justification for requiring genetic testing or disclosure of the same, then this justification could be accepted based on the state of the current legislation.

In addition to the *bona fide* occupational requirement justification described, the Ontario *Human Rights Code* at section 25 states:

- (1) The right under section 5 to equal treatment with respect to employment is infringed where employment is denied or made conditional because a term or condition of employment requires enrolment in an employee benefit, pension or superannuation plan or fund or a contract of group insurance between an insurer and an employer, that makes a distinction, preference or exclusion on a prohibited ground of discrimination.
- (2) The right under section 5 to equal treatment with respect to employment without discrimination because of sex, marital status or family status is not infringed by an employee superannuation or pension plan or fund or a contract of group insurance between an insurer and an employer that complies with the *Employment Standards Act, 2000* [SO 2000, c 41] and the regulations thereunder.

Effectively, these sections allow discrimination on the basis of age, marital status and sex as listed under the *Employment Standards Act, 2000* and the related regulations. The sections are intended to ensure that employability is not affected by discrimination in the context of insurance. These provisions and regulations provide authority for an employer to offer a benefit plan that distinguishes between employees on the basis of age, sex or marital status (i.e. section 44). Section 25 goes on to state:

- (3) The right under section 5 to equal treatment with respect to employment without discrimination because of disability is not infringed,
 - (a) where a reasonable and *bona fide* distinction, exclusion or preference is made in an employee disability or life insurance plan or benefit because of a pre-existing disability that substantially increases the risk;
 - (b) where a reasonable and *bona fide* distinction, exclusion or preference is made on the ground of a pre-existing disability in respect of an employee-pay-all or participant-pay-all benefit in an employee benefit, pension or superannuation plan or fund or a contract of

⁷ For example see *Milazzo v Autocar Connaisseur* (2003) 47 C.H.R.R. D/468; *Entrop v. Imperial Oil*, [2000] 50 O.R. (3d) 18 C.A.

group insurance between an insurer and an employer or in respect of a plan, fund or policy that is offered by an employer to employees if they are fewer than twenty-five in number.

(4) An employer shall pay to an employee who is excluded because of a disability from an employee benefit, pension or superannuation plan or fund or a contract of group insurance between an insurer and the employer compensation equivalent to the contribution that the employer would make thereto on behalf of an employee who does not have a disability.

These sections are unique to the Ontario *Human Rights Code*. These provisions were put in place to try to address a factor that would affect employability.

Another issue in the employment context is the concern that mandatory genetic testing or requirements to disclose genetic testing results could lead to exclusion from, or increased premiums for, insurance policies. The question is who should bear the increased costs. Human rights law suggests it should be the employer in the form of an accommodation for an employee with a perceived disability. The strong “undue hardship” jurisprudence in human rights legislation will likely provide the solution for this.

ii. Insurance Law

The seminal case for the relationship between human rights legislation and insurance is the Supreme Court of Canada’s decision in *Zurich v Ontario Human Rights Commission*, [1992] 2 SCR 321. In this case, the Court ruled that it was not discriminatory to raise insurance premiums on the basis of sex, age and marital status because research suggested a greater statistical likelihood of accident rates. In articulating the test for a *bona fide* and reasonable justification, the Court stated that the insurance company must demonstrate:

(a) **[I]t is based on a sound and accepted insurance practice; and** (b) there is **no practical alternative**. Under (a), a practice is sound if it is one which it is desirable to adopt for the purpose of achieving the legitimate business objective of charging premiums that are commensurate with risk. Under (b), the availability of a practical alternative is a question of fact to be determined having regard to all of the facts of the case.

In order to meet the test of “*bona fides*”, the practice must be one that was adopted honestly, in the interests of sound and accepted business practice and not for the purpose of defeating the rights protected under the *Code* (at paras 23-24, emphasis added).

Both Justice L’Heureux-Dube and Justice McLachlin authored dissents. Justice L’Heureux-Dube wrote that exceptions within human rights legislation should be narrowly construed. She went on to state that “discrimination based on statistical correlation is simply discrimination in a more invidious form” (at para 89). L’Heureux-Dube also identified that mileage was a better indicator of risk of accident and since this non-discriminatory alternative existed, the discriminatory practice could not be justified (at paras 110-11). Justice McLachlin, as she was then, held that Zurich’s failure to demonstrate that *no* reasonable alternative existed was dispositive of the

issue (at para 120-122). She wrote that the absence of proof that a non-discriminatory option existed did not satisfy the burden of demonstrating that the discriminatory conduct was the only option.

Of note, the Majority in *Zurich* discussed the challenge of applying human rights law in the context of insurance. The Court stated:

The determination of insurance rates and benefits does not fit easily within traditional human rights concepts. The underlying philosophy of human rights legislation is that an individual has a right to be dealt with on his or her own merits and not on the basis of group characteristics. Conversely, insurance rates are set based on statistics relating to the degree of risk associated with a class or group of persons. Although not all persons in the class share the same risk characteristics, no one would suggest that each insured be assessed individually. That would be wholly impractical. Sometimes the class or group classification chosen will coincide with a prohibited ground of discrimination, bringing the rating scheme into conflict with human rights legislation. The *Code*, in s. 21 [section 22 in the current *Code*] and other sections, has recognized the special problem of insurance. It exempts an insurer from liability for discrimination if based on reasonable and *bona fide* grounds ... (at para 17).

Applying this in the context of genetic discrimination, the Court seems to consider that individual assessments are inappropriate; rather the rates should be set based on the group's collective risk. While the Court made this statement in the context of auto insurance the same principles apply in the context of group insurance. A detailed individual assessment down to the level of one's genes is inappropriate.

Some genetic fairness groups have gone so far as to argue that actuarial tables already account for genetic pre-dispositions. This is because genetic conditions occur in relatively stable rates across society. The risk is not increasing, only the science which enables individuals to identify who is at a greater risk. Thus, an individual assessment is inappropriate. The insurance company already has access to the information regarding the risk of an employee developing a genetic condition.⁸

The *Zurich* test is still applied in the insurance context; this poses a major problem for genetic discrimination cases. For example, *Zurich* was applied in *Olorenshaw v Western Assurance Co*, 2013 HRTO 280. In this case, an elderly driver challenged the insurance scheme in place which charged more for drivers over 80 years old (at paras 2-4). The Tribunal accepted the reasoning in *Zurich* and upheld the insurance company's approach to insuring older drivers differently on the basis of their age.

The jurisprudence seems to support that a lack of a reasonable alternative trumps industry standards. The industry standards should be challenged. The place to challenge these standards may be an employee benefit plan of a Canadian (rather than Ontarian) employer.

⁸ For more information on this argument, see: <<http://www.councilforresponsiblegenetics.org/ViewPage.aspx?pageId=85>; <http://www.ohrc.on.ca/en/discussion-paper-human-rights-issues-insurance/human-rights-issues-insurance>>; J. Beckwith & J.S. Alper, "Reconsidering Genetic Antidiscrimination Legislation" (1998) 26 J. L., Med. & Ethics 205 at 208.

Currently, the standard of group benefit insurance is based on the size of the group and the grounds/amounts of the policy rather than an absolute distinction based on the members of the group. There is no cost (undue hardship) when the risk is spread equitably across the insurance industry. The failure to spread this risk across the industry affects the employability of certain would-be employees.

Thus, in order to ensure better protection for genetic discrimination claimants in the insurance context, *Zurich* will need to be revisited and likely disarmed. Given the similarity between the “reasonable alternative” component of the test articulated in *Zurich* and the “undue hardship” stage of the test articulated in *Grismer* and *Meiorin*, there is strong support that the element of “undue hardship” should be accounted for in the “no practical alternative” stage of the *Zurich* test. If this approach were taken, it would be more difficult to justify discriminatory practices in the insurance context, especially given the recent jurisprudence which sets such a high standard for “undue hardship” (see for example *Council for Canadians with Disabilities v VIA Rail*, 2007 SCC 15).⁹

While not genetically linked, the Tribunal in the *J v London Life Insurance Co* case cited above applied the *Zurich* test. The Tribunal held that London Life failed to meet the “no reasonable alternative” stage of the test:

... J. points to the fact that, in 1995, another company was prepared to insure his life. J. says that no change in industry standards occurred between 1994 and 1995 that would justify London Life's refusal of coverage for him. J. says London Life has not met its onus of proving its policy was sound because it has failed to introduce the statistical data to establish the existence of a risk. Rather, London Life relies upon the absence of evidence to justify its decision. J. says that, in the absence of actuarial and statistical evidence establishing the risk of insuring him, London Life cannot defend its practice of refusal. No actuary has come forward to say that he sought to ascertain the risk and were unable to do so. Rather, the insurance company says it could not assess the risk, and consequently did not have to insure people in J.'s situation. J. says that the evidence led by the insurance company (that it proceeded on the assumption that it could not quantify the risk) was only anecdotal, and cannot justify its approach (at para 55).

Thus in the insurance context, it will be difficult to overcome *Zurich* and demonstrate that discrimination has occurred without a justification in the context of genetic predispositions. Likely only a case challenging *Zurich* in light of the recent human rights jurisprudence will result in changes that ensure a better balance between the rights and dignity of the individual and the business interests of insurance companies.

It is also important to recognize that prohibiting genetic testing in the insurance context is a bit of a double-edged sword. For example, individuals with a family history of Huntington's disease, which would be disclosed to the insurer, often have difficulty obtaining medical evidence. If

⁹ Note that race and religion, are currently listed as a ground upon which insurers are prohibited from discriminating on; disability is not (*Insurance Act*, RSO 1990, c. I.8, s.140). Further, in auto insurance, discrimination is permitted on the basis of sex, marital status and age. Discrimination on the basis of disability is thus, prohibited.

genetic testing was allowed, individuals who test negative for the gene would have an easier time being approved for affordable insurance that was previously unavailable because of their family status. While arguments could be made regarding discrimination on the basis of family status, the overall scheme of insurance law would be rendered useless if the insurance companies were unable to distinguish between individuals in order to make reasonable decisions about the degree of risk needing to be insured. These competing interests will have to be balanced.

III. WHAT AREAS ARE RIPE FOR PRECEDENT SETTING LITIGATION?

Given the challenges described above, there are a few areas that are ripe for precedent setting litigation based on the human rights of persons with genetic predispositions. Such litigation would raise the public awareness of the hardships and injustices resulting from genetic discrimination, this is the case whether the litigation is successful or not. Either way, litigation will demonstrate the need for legislative action in this area.

The areas for litigation can best be described in terms of a spectrum. On one end is employment law. Based on the human rights principles above, this would likely be the most straightforward area to litigate. A genetic predisposition has been recognized as a disability or perceived disability. An employer would thus have the obligation to accommodate this perceived disability to the point of undue hardship.

The next section of the spectrum would be employment benefits where the employer pays. Again, for the same reasons described above, the employer would have to pay for any increase in benefit costs up to the point of undue hardship.

The issue of employee benefit programs where the employee contributes is more complex. Generally the individual claims in these plans are small. However there are side issues such as independent medical examinations. Generally, employers can request these under certain circumstances. The issue of how in depth these examinations should be allowed to go (i.e. to the genetic level or not) would have to be decided. Further, generally there is a precondition that pre-existing issues are covered unless recently uncovered. These are not covered based on the principle of insurable interest; a foundational principle in insurance law. There is no insurable interest because there is no risk but rather a guarantee that a person will need to rely on the benefits plan.

The final area for litigation is the most complex. It involves dismantling the *Zurich* approach and bringing justifications for discrimination in the insurance context in line with the justifications under human rights legislation in other contexts such as the *bona fide* occupational requirement. Such a case would have to demonstrate that a reasonable alternative to discrimination does exist. Spreading the risk across all insurance companies, would ensure that there is a level playing field for all insurance companies and that adequate protection would be provided for individuals with genetic predispositions to various diseases. The risk would be spread across the insurance companies and the cost passed down to consumers.

IV. GENETIC DISCRIMINATION: INTERNATIONAL APPROACHES

Canada has the opportunity to structure its response to the issue of genetic discrimination based on the approaches taken in other jurisdictions such as the United States, United Kingdom and the European Union.

In the United States, the *Genetic Information Non-Discrimination Act*, 29 US Code s.1182 (2008), protects employees and individuals applying for employment from being discriminated against on the basis of genetic information (ss. 202, 203). The *Act* states that an insurer offering group insurance “may not establish rules for eligibility (including continued eligibility) of any individual to enroll under the terms of the plan based on any of the following health status-related factors in relation to the individual or a dependent of the individual . . . genetic information”. The US approach also provides protection for the privacy of genetic testing results in some states.

The approach in the United Kingdom is characterized by the *Concordat and Moratorium on Genetics and Insurance*. This is a voluntary agreement signed by UK insurance companies to commit to a moratorium on requiring disclosure of genetic testing results where they exist. However, this only applies for policies up to a certain monetary limit. The next review of this policy is set to occur in 2016 but the moratorium will be in place at least until 2019.¹⁰

The approach in the European Union has been framed largely by the Council of Europe’s *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine*, 1997. Other European Union countries have implemented legislation that prohibits the use of genetic testing or consideration of genetic testing results in the context of insurance (i.e. Austria, Belgium and Norway). The legislation prohibits the requirement and or use of genetic testing results in insurance contracts. This also prevents insurers from offering a lower rate on the basis of an individual’s lack of genetic markers for a disease.¹¹

V. CONCLUSION

Canada is behind in the implementation of protections from genetic discrimination. Discrimination in general, insurance law and discrimination in the employment context all represent areas that would benefit from greater protections prohibiting genetic discrimination. As should be clear, the failure to act has the potential to result in profound and negative consequences. Other areas requiring further consideration include the issue of privacy of genetic testing results. For example, if an identical twin was tested, his or her results should be protected by privacy legislation to ensure that it is not accessible to the employer or insurer of the other twin. Failure to have such legislation could result in a subset of the population facing discrimination without choosing to undergo testing themselves.

Given what is at stake and the examples provided by other jurisdictions, Canada needs to address this issue and find a way to protect individuals who may be at risk of adverse treatment and discrimination on the basis of their genetic make-up.

¹⁰ Available online <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216821/Concordat-and-Moratorium-on-Genetics-and-Insurance-20111.pdf>.

¹¹ See Lemmens beginning at para 20.