

# With Great Knowledge Comes Great Responsibilities: An Examination of Genetic Discrimination in Canada

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*Today, we are learning the language in which God created life; we are gaining ever more awe for the complexity, the beauty, the wonder of God's most divine and sacred gift.<sup>1</sup>*

## 1. Introduction

These reverential words were spoken by Bill Clinton at a press conference to announce that a scientific effort to sequence the human genome, termed the “Human Genome Project,” had met with success. In 2001, the entire human genome was sequenced independently by an international consortium of public scientists and a private company (Celera Genomics). While their efforts have been heralded by some as a milestone in the understanding of genetics, disease diagnosis and treatment, there has also been recognition that this technology has the potential to undermine human dignity by creating a new ground for discrimination; one based on an individual’s genetic information.<sup>2</sup> Currently, the threat of genetic discrimination is not pressing as a result of technological limitations, restricted access and availability of genetic information. However, as genetic technologies become more efficient and cheaper the availability of genetic information will become ubiquitous and unfortunately, the problem of genetic discrimination more real.

This paper will examine the status of protections against genetic discrimination under the human rights regime in

Canada. Specifically, I will argue that human rights legislation creates a paradigm based on an anti-discrimination model which is insufficient to deal with the complexities of genetic discrimination as it does not create a strong enough prohibition against genetic discrimination. Moreover, the human rights tribunals that administer this model lack the scientific expertise that is essential to an analysis of genetic discrimination. Finally, the anti-discrimination model is unable to prevent discrimination in a prospective manner.

## 2. What Is Genetic Information

The understanding of basic genetics is integral to discussions pertaining to genetic discrimination. In the most general sense, a gene is a sequence of deoxyribonucleic acid (DNA) located in a particular position on a particular chromosome inside a cell.<sup>3</sup> Genes control the production of proteins and in doing so determine aspects of anatomy and physiology.<sup>4</sup> Variations or mutations of genes may cause abnormalities, the symptoms of which are categorized as a ‘disease.’ Despite hyperbole to the contrary, the study of genetics remains in its infancy. As Stephen J. Gould points out:

Most genes influence several aspects of anatomy and behavior—as they operate through complex interactions with other genes and their products, and with environmental factors both



within and outside the developing organism. We fall into a deep error, not just a harmless oversimplification, when we speak of genes “for” particular parts or behaviors. No single gene determines even the most concrete aspect of my physical anatomy, say the length of my right thumb.<sup>5</sup>

Similarly, there are a number of factors, both biological and environmental, that may influence whether a particular mutation will cause a disease and the severity of the symptoms associated with it. For example, some diseases are mono-genetic, meaning that they are the result of a single mutation in a single gene; others are poly-genetic, meaning that they are the result of multiple mutations, either within a single gene or in different genes.<sup>6</sup> Moreover, some mutations have “incomplete penetrance,” which means that some individuals with the mutation will have no symptoms of the disease.<sup>7</sup>

At this stage, genetic research is mostly focused on discovering connections between specific genetic markers and diseases.<sup>8</sup> Genetic tests identify individuals with specific genetic markers. Therefore, the current predictive power of genetic tests to determine whether an individual will develop a disease or identify the severity of symptoms is quite limited.<sup>9</sup> It is anticipated that the predictive power of these tests will increase as our understanding of genetics becomes more sophisticated, enabling significant advancements to occur in the treatment and diagnosis of disease.<sup>10</sup> However, as outlined by Trudo Lemmens, as genetic technologies advance there is also the threat that “[t]he capacity to conduct [genetic] tests quickly and, more importantly, cheaply will boost demand, commercial production and distribution of the tests, making it potentially cost-effective to introduce genetic screening in a variety of non medical settings.”<sup>11</sup> I suggest that addressing the misuse of genetic information in these settings should be the focus of human rights legislation.

### 3. What Is Genetic Discrimination

Genetic discrimination, in its broadest sense, is the term used to describe people who are treated differently because of their genetic traits.<sup>12</sup> For the purposes of this paper, the term genetic discrimination does not include discrimination based on physical manifestations of genetic traits – as this form of discrimination is already covered by other grounds in Canadian human rights legislation, namely disability.<sup>13</sup>

Genetic discrimination tends to arise in two main contexts, employment and insurance. Employers may use genetic information to influence hiring and promotion practices. In particular, employers may wish to avoid hiring or advancing individuals with certain genetic markers which are linked to conditions that may have an impact on their productivity. Similarly, insurers may choose not to extend insurance benefits or charge higher premiums to individuals with genetic predispositions to certain diseases. In the health care context, the government’s refusal to provide individuals with access to certain genetic tests and/or gene therapies may also be discriminatory; however, a discussion of this issue is beyond the scope of this paper.

### 4. Genetic Discrimination and the Anti-discrimination Model

The concerns about genetic discrimination outlined above have not been explicitly dealt with by Canadian courts or human rights tribunals. Nonetheless, Canadian courts have expanded the existing concepts of discrimination and disability to create a framework that provides some general protections against genetic-based discrimination in Canada. For the purpose of this paper, I will refer to this approach as the “anti-discrimination model.”

The starting point for the recognition of genetic discrimination can be traced to the decision of the Supreme Court of Canada [SCC] in *Andrews v. Law Society of British Columbia*. In that case, the court provided an authoritative definition of discrimination. Specifically, the Court held that

...discrimination may be described as a distinction, whether intentional or not but based on grounds relating to personal characteristics of the individual or group, which has the effect of imposing burdens, obligations, or disadvantages on such individual or group not imposed upon others, or which withholds or limits access to opportunities, benefits, and advantages available to other members of society. Distinctions based on personal characteristics attributed to an individual solely on the basis of association with a group will rarely escape the charge of discrimination, while those based on an individual’s merits and capacities will rarely be so classed.<sup>15</sup>



The focus on the effect of behavior on the complainant versus the *motivation* of the discriminator identified in *Andrews* has been, and continues to be, a fundamental tenet of the Canadian approach to discrimination.<sup>16</sup>

In *Montréal* and *Broisbrand*, the SCC applied the notion of “effects” to the concept of disability. In the first case, the City of Montreal denied two applicants employment after pre-employment medical examinations revealed they had a spinal column anomaly, despite the fact that both individuals were asymptomatic. In the second case, the City of Broisbrand terminated the employment of an asymptomatic police officer diagnosed with Crohn’s disease. In both cases, all of the individuals were able to actively fulfill the duties of the jobs in question. The issue before the court was whether these asymptomatic conditions constituted a “handicap” or “disability.” Ultimately a unanimous SCC held that these individuals had been discriminated against on the basis of disability. In reaching such a decision the SCC emphasized that the notion of disability should be a fluid one. Specifically Justice L’Heureux-Dubé cautioned:

Instead of creating an exhaustive definition of this concept, it seems more appropriate to propose a series of guidelines that will facilitate interpretation and, at the same time, allow courts to develop the notion of handicap[disability] consistently with various biomedical, social or technological factors. Given both the rapid advances in biomedical technology, and more specifically in *genetics*, as well as the fact that what is a handicap[disability] today may or may not be one tomorrow, an overly narrow definition would not necessarily serve the purpose of the [human rights legislation] in this regard.<sup>17</sup>

Essentially, the SCC in *Montréal* and *Broisbrand* extended the notion of discrimination based on disability to include discrimination based on an erroneous *perception* of a complainant’s disability.<sup>18</sup> The approach taken by the SCC is consistent with that taken in the *OHRC*, which statutorily prohibits discrimination based on perceived disability.<sup>19</sup>

In light of Justice L’Heureux-Dubé’s reference to genetic technology in *Montréal* and *Broisbrand*, there has been discussion as to whether the notion of perceived disability can be used to extend protection against genetic-based discrimination.<sup>20</sup> Under current legislation individuals with symptomatic genetic conditions clearly fall under the traditional

ground of “disability” in human rights legislation.<sup>21</sup> The concept of “perceived disability” extends protection to those individuals who have a predisposition to a disease, whether it is genetic in origin or not, but remain asymptomatic.<sup>22</sup> However, what is unclear is what, if any, protection is extended to healthy individuals with genetic markers that indicate they have a *possibility* of developing a disability.

Arguably, by categorizing *Montréal* and *Broisbrand* as a case about potential future disabilities, the SCC’s reasoning can be used to protect against discrimination based on potential future genetic disability. As outlined by Shauna Labman in “Genetic Prophecies”, “while L’Heureux-Dubé J.’s analysis focused on perception, the motivating force behind the discrimination at issue *were* potential future disabilities.”<sup>23</sup> Labman concludes that since the complainants were all currently able to perform the duties of the jobs in question, the employers concerns must have been about their future abilities. The problem with such a categorization, as acknowledged by Labman, is that in *Montréal* and *Broisbrand* all of the individuals did have some “identifiable, manifest problems” and thus, could be categorized as having a present rather than future disability.<sup>24</sup> In contrast, individuals that have genetic markers for diseases may not have any present ‘manifest problem.’ In recognition of the potential limitation of the common law to protect individuals from discrimination based on potential future genetic disability, the Canadian Human Rights Act Review Panel has recommended that the definition of disability in the *CHRA* be amended to include *predisposition* to being disabled.<sup>25</sup> Such an amendment would protect individuals with a genetic predisposition to a disease, regardless of whether a disability became apparent or not. These developments in Canadian human rights jurisprudence, prominently stemming from *Montréal* and *Boisbriand*, have created a framework for genetic-based discrimination cases to be addressed under the current human rights regime. Further protection is extended by the possibility of the inclusion of a ground of “perceived disability” in human rights legislation.

## 5. Short-comings of the Traditional Anti-discrimination Model

The anti-discrimination model provides a useful starting point for addressing the issue of genetic discrimination; however, the model is fundamentally ill-equipped to address the truly novel nature of genetic discrimination. The three main reasons why the anti-discrimination model is insufficient, as will be explained in this section, is that it does not



create a strong enough prohibition, it relies on decision makers with inadequate expertise, and it has virtually no preventative function.

### 5.1 Insufficient Prohibition Against Genetic Discrimination

Under the anti-discrimination model, genetic discrimination is not necessarily prohibited. For example, in an employment context under this model, if an employer is found to have discriminated against an employee on the basis of genetic predisposition, the employer would have an opportunity to justify their discriminatory behavior. Under Canadian human rights legislation an employer may refuse to hire or terminate individuals who do not meet a *bona fide* occupational requirement (BFOR). Specifically, an employer would have to show that not having a genetic disposition to a particular disease constitutes a BFOR. In *B.C. v. B.C.G.S.E.U.*, the SCC set the test for when a discriminatory standard will qualify as a BFOR.<sup>26</sup> Specifically, the SCC held that the employer must show:

- (1) that the employer adopted the standard for a purpose rationally connected to the performance of the job;
- (2) that the employer adopted the particular standard in an honest and good faith belief that it was necessary to the fulfillment of that legitimate work-related purpose; and
- (3) that the standard is reasonably necessary to the accomplishment of that legitimate work-related purpose. To show that the standard is reasonably necessary, it must be demonstrated that it is impossible to accommodate individual employees sharing the characteristics of the claimant without imposing undue hardship upon the employer.<sup>27</sup>

In the event that an employer is able to establish that not having a genetic predisposition is a BFOR, the genetic based discrimination, in that case, will be held to be lawful. While arguably, in most employment situations, an employer would have a difficult time making such a justification, it is important to bear in mind that the anti-discrimination model does permit some forms of genetic discrimination in the employment context.

The short-comings of the anti-discrimination model are even more pronounced in the insurance context. While there are no reports of systemic genetic testing undertaken by insurance companies in Canada as of yet, there is evidence that individuals with known genetic mutations may have a

difficult time obtaining insurance.<sup>28</sup> For example, in *Audet v. Industrielle-Alliance, Cie d'Assurance Sur la Vie*, the court annulled the life insurance contract of Mr. Tremblay because he failed to advise his insurance company that he had a particular genetic mutation associated with myotonic dystrophy.<sup>29</sup> Mr. Tremblay had participated in a research study, during which time he was advised of the presence of the disease-related mutation. Subsequently when he applied for insurance he indicated that he had no physical or mental anomaly. Although he remained asymptomatic throughout his life and died of causes not related to the disease, the court held that his omission with respect to this mutation amounted to a false declaration. The contract was annulled *ab initio*. The *Audet* case highlights the problems that exist with the non-disclosure of genetic information to insurers. As will be outlined below, under the anti-discrimination model, had Mr. Tremblay actually disclosed his genetic information to his insurer, he could have legally been denied insurance.

In understanding the anti-discrimination model's approach to discriminatory insurance practices, it is important to bear in mind that insurance is an industry based on a risk assessment model, in which those who are deemed to be higher risk pay higher premiums than those at lower risk. Making sound distinctions between individuals based on their propensity for developing a disease or disability is integral to the success of the industry. The SCC in *Zurich Insurance Co v. Ontario*<sup>30</sup> recognized that traditional human rights concepts are difficult to apply in the insurance context. Indeed they held:

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.<sup>31</sup>

However the court also cautioned that “[h]uman rights values cannot be over-ridden by business expediency alone.”<sup>32</sup> Ultimately, the court confirmed that discrimination in insur-



ance may be lawful, provided these distinctions are based on reasonable and *bona fide* grounds [RBFGB]. Furthermore, they stated that a discriminatory insurance practice is a RBFGB if:

a) it 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.<sup>33</sup>

In *Zurich*, the SCC was considering the issue of whether an auto-insurance company could charge higher rates for young, single, male drivers on the basis that they are statistically more likely to be involved in an accident.

At first glance it might seem that the situation with regards to genetic discrimination is different. After all, rather than using class characteristics to make generalizations about an individual's potential risk, an insurance company is using an individual's own genetic information to make conclusions about them. However, as outlined above in "1. What is Genetic Information," the presence of particular genetic markers or mutations does not necessarily mean that an individual *will* develop a disease or disability; rather this identifies that the individual is at *risk* of developing such a condition. Accordingly, by relying on genetic tests, which at this stage do not have substantive predictive certainty, insurance companies are indeed making generalizations about an individual's potential risk based on class characteristics. It follows that insurance companies may be able rely on RBFGB to justify genetic based discrimination. Lemmens outlines how insurance companies could meet the RBFGB test to justify genetic discrimination. Specifically Lemmens suggests:

[s]ince most genetic tests aim at indicating a specific risk factor based on statistical calculations, it would not be difficult for insurance companies to justify the use of genetic information and of genetic testing. Insurers could argue that they have no practical alternative but to obtain the same level of accurate information as may be obtained through genetic testing... Insurers would argue they must be able to use genetic testing to obtain information that insurance applicants might otherwise try to hide.<sup>34</sup>

In summary, while Canadian courts have created a foundation for recognizing genetic discrimination, this is subject to an employer's and insurer's ability to establish a BFOR or RBFGB, respectively. Accordingly the anti-discrimination model does not really prohibit genetic discrimination – it merely restricts its application to particular situations.

## 5.2 Inadequate Expertise

In addition to reservations about the inadequacy of the anti-discrimination model's prohibition against genetic discrimination, there is also concern about the limited scientific expertise of tribunals and courts that administer this model. The SCC has, on a number of occasions, held that human rights tribunals are experts in fact finding.<sup>35</sup> This expertise is, for the most part, sufficient to determine when discrimination based on traditional grounds has occurred. The problem with genetic discrimination is that it is not always clear what constitutes such forms of discrimination.<sup>36</sup> Members of human rights tribunals, who generally are not scientific experts, are ill-equipped to appreciate and differentiate the scientific nature of the field of genetics, without an understanding of which, any of analysis of genetic-based discrimination will be superficial.

As a starting point, in order to assess the merits of a genetic discrimination case, tribunal members would have to understand the nature of genetic information and genetic testing. Unfortunately, within the scientific community there is no consensus as to what constitutes 'genetic information.'<sup>37</sup> Generally, genetic information is thought of as "information resulting from the analysis of an individual's DNA."<sup>38</sup> However, in addition to DNA studies, there are also a number of indirect forms of testing which yield genetic information. As Lemmens and Lisa Austin point out:

The identification of phenotypic characteristics associated with genetic conditions such as cleft palate or Spina Bifida, for example, is a form of genetic testing. 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 urinary 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 as a measurement to determine the presence of a genetic condition such as Tay-Sachs.

Genetic information may also be obtained by studying family medical histories.<sup>39</sup> Indeed, family medical histories have long been collected by both medical professionals and insurance companies in order to predict which disease an individual is likely to inherit. Discrimination that is based upon DNA-based tests would be clearly identifiable as “genetic discrimination,” but what about discrimination that is based on more indirect forms of genetic testing? Moreover, there is considerable debate in the scientific community as to whether all medical information is to some degree genetic in nature.<sup>40</sup> Tribunal members cannot be expected to wade, unassisted, through the plethora of scientific information available to determine if the information in an alleged genetic discrimination case is indeed ‘genetic information.’

Assuming for the moment that a tribunal was able to identify a particular type of information as ‘genetic information’ they would then have to determine which uses of this information would qualify as discriminatory. The anti-discrimination model provides no guidance for determining what genetic discrimination is, or for that matter what constitutes the “use” of genetic information. For example, under the model it is unclear if an individual who refused to undergo genetic testing was denied employment it would constitute genetic discrimination? Moreover, as outlined above in “1. What is Genetic Information,” genetic tests have different predictive abilities. In the future, if we have genetic tests that can predict with certainty what, when and to what degree an individual will be affected by a disease, should we allow employers or insurers to make business decisions based on these tests but not on those that have less certain predictive abilities? The answers to these questions are rooted as much in science as they are in human rights theory. Tribunals and, arguably, the courts lack the expertise to evaluate these double-sided issues. Conceivably, tribunal members may have the capacity to learn about the scientific nature of genetic discrimination inquiries; however, they should not be expected to lay the foundation for how these inquiries will be conducted at the same time. Requiring tribunal members, or courts for that matter, to learn about genetics and develop the policy and procedural framework for dealing with genetic discrimination will result in a piece-meal approach to the issue of genetic discrimination. I would suggest that,

at the very least, tribunal members and courts need to have some legislative guidance on how to address the scientific nature of genetic discrimination.

### 5.3 Lacks Preventative Function

In addition to reservations about the limited scientific expertise of both the tribunals and courts to deal with the issues surrounding genetic discrimination, the anti-discrimination model’s traditional reactionary approach to discrimination is inappropriate when dealing with genetic discrimination. The traditional anti-discrimination model provides remedies for those whose rights have been violated and, in doing so, likely creates a disincentive for others to make similar transgressions. While providing relief to the victims of discrimination is important, it is not the sole goal of human rights legislation. One of the other aims of human rights regimes, which I would argue should be the main goal, is to prevent discrimination before it occurs. As outlined by William W. Black, prevention is preferable to an after-the-fact remedy because “[a]t the very least, it avoids the costs of litigation. It also assists those who for one reason or another are unlikely to file a complaint.”<sup>41</sup>

The complaint based traditional anti-discrimination model is simply unable to prevent discrimination. As P. Florencio and E. Ramanathan point out, rather bluntly, “while discrimination laws provide a disincentive, they are incapable of preventing discrimination.”<sup>42</sup> The inability of the anti-discrimination model to prevent discrimination may be in part due to the history of its development. Traditionally, human rights legislation was developed in response to existing violations of human rights. Indeed the purpose of the *CHRA*, as outlined by J. McIntyre in *Ontario Human Rights Commission*, was the “removal of discrimination.”<sup>43</sup> Implicit in this purpose is an understanding that discrimination existed at the time the legislation was created. I suggest that the anti-discrimination model was not developed with an intention of preventing discrimination because such discrimination was unfortunately omnipresent at the time of its creation.

In contrast, genetic discrimination, at least in Canada, is not rampant but rather is an issue that may become problematic in the future.<sup>44</sup> Unlike the situation with the more ‘traditional’ forms of discrimination, genetic discrimination presents us with an opportunity to take active steps to limit discriminatory behaviors before they become common place.



The novelty of genetic discrimination makes it fundamentally different from traditional forms of discrimination and thus, ripe for a proactive approach to combat discrimination. The issue then becomes: how can we prevent genetic discrimination? The challenge of preventing genetic discrimination is different from other forms of discrimination because for the most part genetic traits, unlike other traits such as race or sex, are not readily discernable. In other words, genetic discrimination cannot exist unless there is access to genetic information. It follows that genetic discrimination can be prevented, or at the very least limited, by controlling access to genetic information.

At first glance it might seem access to genetic information may be controlled by legislation that regulate the use and disclosure of personal information.<sup>45</sup> Indeed, privacy acts exist at both the federal and provincial levels.<sup>46</sup> At the federal level, the *Personal Information Protection and Electronic Document Protection Act (PIPEDA)* controls access to personal information in the private sector. Several authors have examined the insufficiencies of this Act in providing meaningful protection of personal information.<sup>47</sup> I do not propose to detail these criticisms, however, I suggest that even a preliminary glance at this legislation illustrates the manner in which *PIPEDA* cannot effectively control access to genetic information in a way that would substantially help prevent genetic discrimination.

*PIPEDA* functions to restrict the collection of personal information to only those purposes that would be considered appropriate by a reasonable person.<sup>48</sup> The Act requires an organization to obtain the informed consent of individuals prior to the collection and subsequent disclosure of personal information.<sup>49</sup> Under section 11 of the Act, a complainant may file a complaint with the Privacy Commissioner. Following an investigation of the allegations and issuing of a report, the complainant may then apply to the Court for a hearing.<sup>50</sup> The court is limited to ordering the following remedies:

- (a) order an organization to correct its practices in order to comply with sections 5 to 10;
- (b) order an organization to publish a notice of any action taken or proposed to be taken to correct its practices, whether or not ordered to correct them under paragraph (a); and
- (c) award damages to the complainant, including damages for any humiliation that the complainant has suffered.<sup>51</sup>

The remedies available under *PIPEDA* have been criticized as being slow, costly and ineffective and therefore, insufficient to address the concerns of those whose privacy interests have been infringed.<sup>52</sup> Genetic information is even more sensitive than other forms of personal information due to its predictive nature.<sup>53</sup> Not only does genetic information tell us about a person's current medical state but it also reveals information about their future health. Moreover, since family members share similar DNA, genetic tests also reveal information about their present and future health.<sup>54</sup> The ineffectiveness of *PIPEDA* to protect personal information in general makes it an even more unsuitable tool to rely on to protect genetic information.

Moreover, *PIPEDA* is governed by commercial principles, not human rights principles.<sup>55</sup> As a result, it does not incorporate the interpretative principles developed in the context of human rights legislation. In *Robichaud v. Canada (Treasury Board)*, the SCC summarized the principles that should be used to interpret human rights legislation.<sup>56</sup> Specifically, the court said:

As McIntyre J., speaking for this Court, recently explained in *Ontario Human Rights Commission and O'Malley v. Simpsons-Sears Ltd.*, the Act must be so interpreted as to advance the broad policy considerations underlying it. That task should not be approached in a niggardly fashion but in a manner befitting the special nature of the legislation, which he described as "not quite constitutional"; ... More recently still, Dickson C.J. in *Canadian National Railway Co. v. Canada* emphasized that the rights enunciated in the Act must be ... given such fair, large and liberal interpretation as will best ensure the attainment of their objects. [citations omitted]<sup>57</sup>

By not incorporating these principles into its interpretation, *PIPEDA* does not benefit from the broad and liberal interpretive analysis applied in the human rights context. Accordingly, *PIPEDA* is interpreted strictly, as a consequence of which its ability to protect personal information is undermined.



## 6. Conclusions

Preventing genetic discrimination and protecting those who have suffered from such discrimination is certainly a noble and worthy goal. However, in our zest to address this issue, we should be careful not to treat genetic discrimination in the same manner as the more traditional forms of discrimination. The anti-discrimination model was developed in response to existing and widespread discrimination based on these traditional grounds. As discussed above, the situation with genetic discrimination is different from that of traditional forms of discrimination

To be clear, I am not suggesting that the traditional anti-discrimination model should not be applied to genetic-based discrimination. Indeed, it should. The anti-discrimination model serves a useful function in that it creates a structured regime whereby victims of any form of discrimination can seek recourse. However, as outlined above, this model has flaws, unique to the context of genetic discrimination, that need to be addressed. The problem of genetic discrimination requires a comprehensive multi-disciplinary approach. There needs to be recognition that the issue of genetic discrimination is more than just a traditional anti-discrimination issue or a privacy concern – it has a scope that is somewhat amorphous. What is needed is separate legislation, governed by human right principles and enforced by human rights tribunals, dealing explicitly with genetic information and discrimination. Having separate legislation to deal with specific human rights concerns is not a novel idea. Indeed, the pay equity regime under the *CHRA* is one such example of such legislation.

Developing a comprehensive, multi-disciplinary approach to genetic discrimination will not be an easy task. The concerns raised in this paper will haunt any legislative scheme that is developed. However, the difficulty of the task is no reason not to proceed. The advances of the Human Genome Project have given scientist's considerable insight about life, or as Bill Clinton said, "the language of God," it is up to us now to regulate its use; indeed with great knowledge, comes great responsibility.

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1. Bill Clinton, Press Conference, (26, June 2000), on-line: Senior Journal <<http://www.seniorjournal.com/NEWS/2000%20Files/June%2000/FTR-6-27-00CIntnOnGnMap.htm>>.
2. Marvin E. Frazier *et al.*, "Realizing the Potential of the Genome Revolution: The Genomes to Life Program" (2003) 300:5617 *Science* 290; Paul Recer, "Experts fear genome findings" *The Associated Press* (12 February 2001), on-line: <[http://www.theahl.com/CNEWSScience0102/12\\_genes-ap.html](http://www.theahl.com/CNEWSScience0102/12_genes-ap.html)>, see also Paul Recer, "Gene Map creates new frontier for discrimination, experts say" *Canadian Broadcasting Corporation* (11 February 2001), on-line: GENET Archive <[www.genet.info.org/genet/2001/Feb/msg00034.html](http://www.genet.info.org/genet/2001/Feb/msg00034.html)>.
3. U.S., The Human Genome Program, *Human Genome Project Information: Genome Glossary*, on-line: The Human Genome Program <[http://www.ornl.gov/sci/techresources/Human\\_Genome/glossary/glossary\\_g.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/glossary/glossary_g.shtml)>.
4. *Ibid.*
5. Stephen Jay Gould, "Viewpoint: Message from a Mouse" *Time asia* 154: 11 (13 September 1999) 48, on-line:
6. U.S., National Human Genome Research Institute, *Promoting Safe and Effective Genetic Testing in the United States, Final report of the Task Force of Genetic Testing* by Neil A. Holtzman & Micheal S. Watson, eds. (Washington, D.C.: Task Force on Genetic Testing, 1997) at Chapter 1, on-line: National Human Genome Research Institute <<http://www.genome.gov/10002405>>.
7. For example certain mutations of the BRCA 1 gene have been linked to breast cancer; however between 10 to 15% of women with this mutation never develop the disease. See *ibid.* at Chapter 2.
8. Some researchers are also seeking to discover genetic markers associated with certain behavioral and personality traits such as homosexuality, intelligence, etc. See Dean H. Hamer *et al.*, "A Linkage between DNA markers on the X Chromosome and Male Sexual Orientation" (1999) 261 *Science* 321; Ya-Ping Tang *et al.*, "Genetic Enhancement of Learning and Memory in Mice" (1999) 401 *Nature* 63.
9. *Supra* note 6.
10. Francis S. Collins, "Shattuck Lecture : Medical and Societal Consequences of the Human Genome Project" (1999) 341 *New England Journal of Medicine* 28.
11. Trudo Lemmens, "Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes



- in Our Laws?” (2000) 45 McGill L.J. 347 at 351-352, online: McGill L.J. <<http://www.journal.law.mcgill.ca/abs/45/2lemme.html>>.
12. There has been considerable debate as to how to define genetic discrimination, see *ibid.* at 355.
  13. See *Canadian Human Rights Act*, R.S.C. 1985, c.H-6, s.2 [CHRA] and *Human Rights Code*, R.S.O. 1990, c. H.19, s.10(1) [OHRC]. The reason for this distinction will become more apparent in subsequent discussions.
  14. *Andrews v. Law Society of British Columbia*, [1989] 1 S.C.R. 143, 56 D.L.R. (4th) 1 [*Andrews* cited to S.C.R.].
  15. *Ibid.* at 174 [emphasis added].
  16. See *Ontario Human Rights Commission et al v. Simpson-Sears*, [1985] 2 S.C.R. 536, 23 D.L.R. (4th) 321 [*Ontario Human Rights Commission* cited to S.C.R.]; *Law v. Canada (Minister of Employment and Immigration)*, [1999] 1 S.C.R. 497, 170 D.L.R. (4th) 1; *Québec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City) and Québec (Commission des droits de la personne et des droits de la jeunesse) v. Broisbrand (City)*, [2000] 1 S.C.R. 665, 185 D.L.R. (4th) 385 [*Montréal and Broisbrand*].
  17. *Montréal and Broisbrand*, *ibid.* at para. 76 [emphasis added]. The court’s analysis refers to “handicap” as this term appears in the Quebec *Charter of Human Rights and Freedoms*, R.S.Q., c. C-12. In light of the SCC’s emphasis in *Eldrige v. B.C. (Attorney General)*, [1997] 3 S.C.R. 624, 151 D.L.R. (4th) 577 at para. 46 that “mere differences in terminology do not support a conclusion that there are fundamental differences in the objectives of the human rights statutes” the conclusion reached in *Montréal and Broisbrand* are equally applicable to statutes using the term “disability”.
  18. *Montréal and Broisbrand*, *ibid.* at para 48.
  19. OHRC, *supra* note 13. Pursuant to the OHRC, section 10(3) “disability” includes “perceived disability”.
  20. See Shauna Labman, “Genetic Prophecies: The Future of the Canadian Workplace” (2004) 30:2 Man. L.J. 227 at 241-243 [Genetic Prophecies]; The Canadian Biotechnology Advisory Committee, *Genetic, Privacy and Discrimination* by Eugene Oscapeella (Ottawa: Canadian Biotechnology Advisory Committee, 2000) at p.12, online: Canadian Biotechnology Advisory Committee <<http://cbac-cccb.ic.gc.ca/epic/internet/incbac-cccb.nsf/en/ah00347e.html>>.
  21. See CHRA, *supra* note 13 at section 2; OHRC, *supra* note 13 at section 10(1).
  22. One example of predisposition to a disease that is not genetic in origin is the development of AIDS in individuals with the HIV virus.
  23. Genetic Prophecies, *supra* note 20 at 241 [emphasis in original].
  24. *Ibid.* at 242. In the *Montréal* case, the first complainant, Mercier had a minor thoracolumbar scoliosis, the second complainant, Hamaon had anomalies to his spinal column (bilateral spondylolysis and spondylolisthesis L5. In the *Broisbrand* case, the complaint had chronic inflammation of the intestine. *Montréal and Broisbrand*, *supra* note 16.
  25. Canadian Human Rights Act Review Panel, *Promoting Equality: A New Vision* (Ottawa: Minister of Justice and the Attorney General of Canada, 2000) at 101, online: Department of Justice <<http://www.justice.gc.ca/chra/en/toc.html>>.
  26. *British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees’ Union (B.C.G.S.E.U.)*, [1999] 3 S.C.R. 3, 176 D.L.R. (4th) 1.
  27. *Ibid.* at para 54.
  28. *Supra* note 11 at 352.
  29. *Audet v. Industrielle-Alliance, Cie d’Assurance Sur la Vie*, [1990] R.R.A. 500-502 (C.S.).
  30. *Zurich Insurance Co v. Ontario (Human Rights Commission)*, [1992] 2 S.C.R. 321, 93 D.L.R. (4th) 346.
  31. *Ibid.* at para 17.
  32. *Ibid.* at para 36.
  33. *Ibid.* at para 23.
  34. *Supra* note 11 at 406.
  35. *Canada (Attorney General) v. Mossop*, [1993] 1 S.C.R. 554, 100 D.L.R. (4th) 658; *Gould v. Yukon Order of Pioneers*, [1996] 1 S.C.R. 571, 133 D.L.R. (4th) 449; *Ross v. New Brunswick School District No. 15*, [1996] 1 S.C.R. 825, 133 D.L.R. (4th) 1; *University of British Columbia v. Berg*, [1993] 2 S.C.R. 353, 102 D.L.R. (4th) 665.
  36. Indeed, in the most obvious of cases, this expertise may also be sufficient to determine when genetic based discrimination has occurred. An obvious case of genetic discrimination would be one in which an employer orders job applicants to undergo genetic testing and refuses to hire those applicants with certain genetic pre-dispositions.
  37. See J.S. Alper & J. Beckwith, “Distinguishing Genetic From Nongenetic Medical Tests: Some Implications For Antidiscrimination Legislation” (1998) 4 Science and Engineering Ethics 141 at 148.
  38. Canadian Biotechnology Advisory Committee, “Of Volume, Depth and Speed: The Challenges of Genetic



- Information” by Trudo Lemmens & Lisa Austin, (February 2001) at6, online: Canadian Biotechnology Advisory Committee <<http://cbac-cccb.ic.gc.ca/epic/internet/incbac-cccb.nsf/en/ah00346e.html>>.
39. *Ibid.* at 7.
  40. *Supra* note 37.
  41. William W. Black, “Human Rights Reform in B.C” (1997) 31 U.B.C. L. Rev. 255 at para. 20 (QL).
  42. Patrik S. Florencio & Erik D. Ramanathan, “Secret Code: The Need for Enhanced Privacy Protections in the United States and Canada to Prevent Employment Discrimination Based on Genetic and Health Information” (2001) 39 Osgoode Hall L.J. 77 at para. 19 (QL).
  43. *Ontario Human Rights Commission, supra* note 16 at 547.
  44. In the 1970’s in the United States there was discrimination against carriers of sickle cell anemia trait under the belief that they were more vulnerable to certain chemical. See Joanne Selzter, “The Cassandra Complex: An Employer’s Dilemma In the Genetic Workplace” (1998) 27 Hofstra L. Rev 411.
  45. There has been some suggestion that the *Canadian Charter of Rights and Freedoms*, Part 1 of the *Constitution Act*, 1982, being schedule B to the *Canada Act 1982* (U.K.), 1982, c.11 protects an individual’s right to reasonable privacy. Specifically, Barbara von Tigerstrom argues that section 8 of the Charter to be “secure against unreasonable search and seizure and section 7 guarantee of life, liberty and security of the person may include privacy interests. However she notes that the SCC has been reluctant to make an affirmative stand on these issues. See Barbara von Tigerstrom, “*Protection of Health Information Privacy: The Challenges and Possibilities of Technology*” (1998) 4 Appeal 44 at para. 9 (QL).
  46. At the federal level parliament has enacted the *Personal Information Protection and Electronic Document Protection Act*, S.C. 2000, c.5 [PIPEDA]. Similarly a number of provinces have enacted privacy legislation to protect information held by public bodies in some cases the private sector. See Ontario, *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31; British Columbia, *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165; Saskatchewan, *Freedom of Information and Protection of Privacy Act*, S.A. 1994, c. F-18.5; Quebec, *An Act Respecting Access to Documents Held By Public Bodies and the Protection of Personal Information*, R.S.Q. 1998, c. A-2.1, Quebec, *An Act Respecting the Protection of Personal Information in the Private Sector*, R.S.Q. 1998, c. P-39.1; and Manitoba, *Personal Health Information Act*, S.M. 1997, c. 51.
  47. See Teresa Scassa, “Text and Context: Making Sense of Canada’s New Personal Information Protection Legislation” (2000-1) 32 Ottawa L. Rev.1; Bartha Maria Knoppers & Genevieve Cardinal, “Genetics and the Law” in Jocelyn Downie, Tim Caulfield & Colleen Flood, eds., *Canadian Health Law and Policy*, 2d. ed. (Markham, Ont.: Butterworths, 2002) 433 at 442; *supra* note 42 at para. 43; *Genetic, Privacy and Discrimination, supra* note 20 at page 11.
  48. *PIPEDA, supra* note 45 at ss.3, 5(3).
  49. *Ibid.*, s.4.3.1.
  50. *Ibid.*, s.14.
  51. *Ibid.*, s.16.
  52. See D. Flaherty, *Protecting Privacy in Surveillance Societies: The Federal Republic of Germany, Sweden, France, Canada, and United States* (Chapel Hill: University of North Carolina Press, 1989) at 385; Christopher Berzins “Protecting Personal Information in Canada’s Private Sector: The Price of Consensus Building” (2002), 27 Queen’s L.J. 609 at para. 64 [“Protecting Personal Information”]; Health Canada, *Selected Legal Issues in Genetic Testing: Guidance from Human Rights* by Derek J. Jones (Ottawa: Health Canada, 2001) at 19, online: Health Canada <<http://www.hc-sc.gc.ca/iacb-dgiac/arad-draa/english/rmdd/wpapers/jones.html>>.
  53. Some authors argue that all medical information shares these characteristics of genetic information and thus should be afforded the same protections that may be extended to genetic information. See T. Murray, “Genetic Secrets and Future Diaries: Is Genetic Information Different from Other Medical Information” in M..A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997) 60; *supra* note 38.
  54. *Supra* note 38.
  55. See “Protecting Personal Information”, *supra* note 52. Berzin points out at the time of the drafting of *PIPEDA* there was debate whether the legislation should be governed by commercial or human rights principles. At paragraph 33, he argues that *PIPEDA* was a “commercially-driven piece of legislation”.
  56. *Robichaud v. Canada (Treasury Board)*, [1987] 2 S.C.R. 84, 40 D.L.R. (4th) 577.
  57. *Ibid.* at para. 8.

