

Genetic Prophecies: The Future of the Canadian Workplace

SHAUNA LABMAN*

“EACH NEW POWER WON BY MAN IS A POWER OVER MAN AS WELL.”
C.S. LEWIS, *THE ABOLITION OF MAN*¹

I. INTRODUCTION

Prominent Harvard biologist Walter Gilbert, a leader of the Human Genome Initiative, likened the project of mapping the human genome to the quest for the “Holy Grail” of human identity.² Yet, if we are to turn back to Arthurian legend, we should not forget another aspect of the myth: Excalibur, the double-edged sword of the King, likewise deserves a place in our visions of genetic advancement. Mapping the human genome marks only the beginning of a new era in genetic understanding³ and the genome is now medicine’s most powerful weapon to fight disease.⁴ At the same time, however, these advancements carry

* Shauna Labman is a graduate of the University of Victoria Faculty of Law. She is currently a law clerk at the Federal Court of Appeal.

¹ C.S. Lewis, *The Abolition of Man* (New York: Macmillan Company, 1947) at 71.

² Walter Gilbert, “A Vision of the Grail”, in Daniel J. Kevles & Leroy Hood eds., *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge: Harvard University Press, 1992) at 96.

³ On 12 February 2001 *The New York Times* leaked the news that the two competing projects to sequence the human genome were about to announce on that day that the genome had been successfully mapped. See Richard Lewontin, *It Ain’t Necessarily So: The Dream of the Human Genome and Other Illusions*, 2nd ed. (New York: New York review Books, 2001) at 187.

⁴ Deoxyribonucleic acid (DNA) is the basic building block of genes. The human genome refers to the twenty-three pairs of chromosomes that all humans carry and within which all genes reside. Disease can result from the variation and alteration in the genes, known as mutations. The Human Genome Project succeeded in “mapping” the DNA sequences in the human body. This has helped to identify many genes that cause disease. Scientists are able to take blood from an individual, identify variations between that person’s gene sequence and a normal gene sequence, and make predictions about that individual’s susceptibility to different diseases or conditions. See George P. Smith, II and Thaddeus J. Burns, “Genetic Determinism Or Genetic Discrimination?” (1994) 11 J. Contemp H. L. &

with them the danger of genetic discrimination which, at its extreme, could lead to a new social division and the emergence of a "genetic proletariat".⁵

This paper examines how genetic testing affects the Canadian workplace. Beginning with a summary of what is meant by genetic testing, I will then show how an employer could use the knowledge obtained through such tests, leading to potentially disastrous consequences for the workforce and, more broadly, for society at large. Turning to the legal responses to such consequences, I will recognize two complimentary options: first, privacy legislation; and secondly, the anti-discrimination provisions of human rights legislation. Access to genetic testing and test results must be regulated through privacy legislation; yet an exclusive focus on privacy is misguided. Current and proposed legislation may not secure against access to genetic information in all employment situations. When genetic testing occurs, or if results are released, the information must not be misused. Consideration must be given to whether the ability of the anti-discrimination provisions of existing human rights legislation can protect against genetic discrimination once genetic information has been obtained. I will argue that the existing prohibition against disability discrimination, within human rights codes, can and should be interpreted and applied to encompass genetic discrimination. I conclude that this option is preferable to creating gene-specific legislation. For science to achieve its laudable goals without sacrificing human dignity, the law must stay abreast of these developments and ensure that adequate protections are in place.

II. GENETIC TESTING

Before any discussion can take place, it is necessary to understand the prophetic capacities of genetic testing, as well as its limitations. For over twenty years, the blood of North American newborns has been tested for conditions, which if treated immediately, can prevent severe mental handicap or other deadly diseases.⁶ However, suggestions that a sample of blood, skin, or hair is all that will someday be necessary to reveal a history yet un-lived is creative fancy. Trudo Lemmens points to the reality that "[t]here is no such thing as the genetic test result"⁷ because a varying range of certainty exists with different genetic tests. Huntington's disease, for example, is a dominant, single-gene disorder; and

Pol'y at 29 and Deborah Gridley, "Genetic Testing Under the ADA: A Case for Protection from Employment Discrimination" (2001) 89 Geo. L.J. 973.

⁵ Bartha Maria Knoppers, "Picard Lecture in Health Law - 1992: Human Genetics: Parental, Professional and Political Responsibility," (1993) 1 Health L.J. 13 at 14.

⁶ *Ibid.* at 15.

⁷ Trudo Lemmens, "Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?" (2000) 45 McGill L.J. 347 at para 49.

consequently, the gene mutation is a strong and predictable indication that the individual will develop the disease. Other single gene mutations and complex polymorphisms may indicate merely an increased chance of developing a corresponding disorder. Moreover, some diseases are curable while others may be preventable through diet and environment.⁸ Joseph Alper and Jon Beckwith indicate that “the environment, gene-environment covariance, and gene-environment interactions can be as important as genes and gene-gene interactions in determining the expression of these conditions.”⁹

A *geno passport* was the claimed offering of the Genometrics Corporation, the first Canadian genetic testing operation that opened in Saskatoon in October 2001.¹⁰ For a fee of \$1 500, the offered test would screen for 1 700 diseases and tell customers which conditions they are most likely to contract.¹¹ Patricia Baird, a professor at the University of British Columbia and a leading Canadian geneticist, criticized the Saskatoon facility for selling useless information:

Even though genetic testing is very accurate, it's not useful most of the time. Having a gene that so-called predisposes you to something isn't very useful because many people with that gene will never ever come down with the disorder and many people who don't have the gene will.¹²

In the absence of predictive certainty, genetic screening can have the effect of creating a population of the “healthy sick.”¹³ While some within this category will eventually fall ill, others will carry with them only the shadowed threat of a disease that will never develop. For the most part then, genetic testing may offer the benefit of a warning, enabling the ‘marked’ to take preventive measures, but no definite view into the future can be provided—a fact that must accompany any consideration of genetic testing in the workplace.

⁸ *Supra* note 7.

⁹ Joseph Alper and Jon Beckwith, “Distinguishing Genetic from Nongenetic Medical Tests: Some Implications for Antidiscrimination Legislation,” (1998) 4(2) *Sci. Eng. Ethics* at 146.

¹⁰ Tom Arnold, “Firm Brings First Private Gene-Testing To Canada” *The National Post* (6 October 2001) A1 at A1. The company no longer appears to exist and the *Saskatchewan Gazette*, May 31, 2002 notes it as struck off the register.

¹¹ *Ibid.* at A1.

¹² *Ibid.* at A14.

¹³ Maureen A. McTeer, *Tough Choices: Living and Dying in the 21st Century*, (Toronto: Irwin Law, 1999) at 47.

III. THE PROBLEM

Completion of the Human Genome Project rapidly increased the pace of genetic research, opening the door to a broad range of previously impossible tests at increasingly affordable prices.¹⁴ In the United States, genetic testing is a growing trend in the workplace. The American Civil Liberties Union cites an American Management Association survey finding that 6 to 10 percent of American employers conducted genetic testing in 1997. In a similar survey, published in 1996, approximately 22 percent of close to 1 000 individuals, at risk for genetic conditions, reported some form of discrimination.¹⁵ In his report on genetic testing and privacy in 1992, the federal Privacy Commissioner found that there was little genetic testing in the Canadian workplace.¹⁶ Over a decade later, private genetic testing facilities have opened.¹⁷ In November 2001, the Canadian Bar Association ran a cover story in its *National* magazine, titled "The Genetic Dilemma", in which the author suggested, "As researchers discover the genetic flaws associated with cancers and many other diseases, a variety of issues—the right to privacy and informed consent, the redress of negligence and discrimination—are emerging to preoccupy both politicians and lawyers."¹⁸

¹⁴ Genetic discoveries of the past few years have included: the discovery of a salt gene that could explain why some people with high blood pressure respond to a low-salt diet, and others do not; a finding that black smokers appear to absorb more nicotine than white smokers, which could explain why black smokers have more trouble quitting and run a higher risk of lung cancer; a report that people who are depressed may have been born with a genetic predisposition not to be happy; a discovery about several genetic defects that increase the tendency to put on weight; a report about a genetic mutation that can cause heart failure; a report that a novelty-seeking gene may influence sensation-seeking in adults; a finding that one gene plays a key role in inflammatory breast cancer; a finding that even dark-skinned people who carry certain genetic variations are at increased risk for skin cancer; and the discovery that alteration of a specific gene appears to contribute to both the common late-onset form of Parkinson's disease, and the rarer, early-onset form of the disease. See Eugene Oscapella, *Genetics, Privacy and Discrimination A Survey Prepared for the Canadian Biotechnology Advisory Committee Project Steering Committee on Genetic Privacy*, October 2000 at 8, online: <http://cbac-cccb.ca/epic/internet/incbac-cccb.nsf/vwGeneratedInterE/ah00347e.html> (accessed November 16, 2003).

¹⁵ American Civil Liberties Association, *Genetic Discrimination in the Workplace Fact Sheet*, online: <http://archive.aclu.org/issues/worker/gdfactsheet.html> (accessed November 16, 2003)

¹⁶ Privacy Commission of Canada, *Genetic Testing and Privacy*. (Ottawa: Minister of Supply and Services, 1992).

¹⁷ Tom Arnold, "Firm Brings First Private Gene-Testing To Canada" *The National Post* (6 October 2001) at A1.

¹⁸ Sheldon Gordon, "The Genetic Dilemma" *National* 10:7 (November 2001) at 23.

Though Canadian employers are not faced with the same incentive to screen for genetic markers as American employers who must provide health care,¹⁹ disabled employees nevertheless pose inconvenience and cost to Canadian employers. Human rights legislation imposes on employers a duty to accommodate disability, short of undue hardship;²⁰ and increased costs of accommodation has been held insufficient to qualify as undue hardship.²¹ Thus, a Canadian employer might be faced with added costs to maintain a disabled employee. Potential disabilities, that may later create medically related absences, departure from the company, or demands for accommodation, can act as a hiring dissuasion. Similarly, an employer does not want to invest in training employees that will be unable to work in the future due to illness. Genetic markers could, also alleviate employer responsibility for certain workplace dangers if employers could screen for predispositions to risk. The ability to use genetic testing to assess the potential consequences of workplace contaminants—radiation for example—might also help employers avoid later payments for work-related illness.

A consideration of an employer's legal responsibility exposes a dilemma in the argument against testing or access to results. There is a burden placed on employers by occupational health and safety standards and workers compensation acts to ensure the health and safety of their employees. Genetic screening could be rationalized where there is a risk of genetic vulnerability to occupational illnesses that stem from routine workplace exposure to harmful toxins or chemicals.²² Joanne Seltzer has coined the phrase "Cassandra

¹⁹ The American literature often offers the provision of Universal Health Care as a solution that would remove the incentive for employers to require testing. See Jon Beckwith, Joseph S. Alper, "Reconsidering Genetic Antidiscrimination Legislation" (1998) 26 J.L. Med. & Ethics 205 at 208. Yet, even in Canada approximately 30 percent of the costs of care are privately paid. See C. Fuller, *Caring for Profit: How Corporations are Taking Over Canada's Health Care System* (Vancouver: New Star Books, 1998) at 98 qtd in P. Florencio and E. 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 fn 22. As well, different benefit plans exist in Canada, including some that do require the employers to pay for coverage.

²⁰ *British Columbia (Public Service Employee Relations Commission) v. B.C.G.E.U.* (1999), 176 D.L.R. (4th) 1 (S.C.C.) at 24–25 ("Meiorin").

²¹ *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, [1999] 3 S.C.R. 868.

²² See J. Richter, "Taking the Worker as You Find Him: The Quandary of Protecting the Rights as well as the Health of the Worker with a Genetic Susceptibility to Occupational Disease" (1997) 8 Md. J. Contemp. Legal Issues 189; Lorie M. Pesonen, "Genetic Screening: An Employer's Tool to Differentiate or to Discriminate?" (2002) 19 J. of Contemp Health Law & Pol. 187. As a rationale for testing this reasoning currently lacks support. A study by the Federal Privacy Commission reported that, in the Canadian

Complex” for the employer “of the next millennium,” who “will face the prospect of liability for failing to act on the genetic information he is statutorily pre-empted from accessing.”²³ Seltzer examined two companies who both faced condemnation: one for using the results of screening techniques, the other for failing to do so.

Faced with the fear in the 1970s that carriers of the sickle-cell trait may be more vulnerable to certain hemolytic agents, Du Pont de Nemours & Co. (“Du Pont”) screened African-American applicants with pre-employment blood tests to identify carriers of the sickle-cell gene. Only African-American applicants were screened—a fact justified by Du Pont on the basis that it was a group of African-American employees who had originally requested the tests.²⁴ Du Pont also conducted certain enzyme deficiency tests for conditions prevalent among people of Northern European ancestry.²⁵ These tests were used by Du Pont to aid in work placements and re-assignment, and the results were filed with the medical records of the employee.²⁶ Du Pont suffered the scrutiny of congressional hearings investigating the existence of genetic screening in the workplace and received constant attention from the *New York Times*.²⁷ The company was attacked for its “eugenic policy” and accused of “scientific racism.”²⁸

Seltzer contrasts Du Pont’s experience with that of a second company also conducting genetic tests. Dow Chemical Company (“Dow”) tested thousands of workers to determine if “defective” genes made them more susceptible to workplace substances.²⁹ The Dow tests led researchers to believe that workers who exhibited consistently high rates of broken chromosomes should be notified and transferred away from the chemicals that may have caused their chromosomal mutations. The leading researcher indicated that Dow became

context, there is “no employment situation that warrants the compulsory or voluntary collection of personal genetic information for the benefit of employers. Without compelling arguments to the contrary, genetic screening for the benefit of the employer is inappropriate.” (Privacy Commission of Canada. *Genetic Testing and Privacy*. (Ottawa: Minister of Supply and Services, 1995) at 31, online: http://www.privcom.gc.ca/information/02_05_e.asp (accessed November 16, 2003)).

²³ Joanne Seltzer, “The Cassandra Complex: An Employer’s Dilemma In The Genetic Workplace” (1998) 27 *Hofstra L. Rev.* at 411.

²⁴ *Ibid.* at 420.

²⁵ *Ibid.*

²⁶ *Ibid.* at 422.

²⁷ *Ibid.* at 419.

²⁸ Jonathan King, qtd in Seltzer *ibid.* at 422.

²⁹ *Ibid.* at 422.

hostile and distant upon learning of the results and that he and his colleagues eventually left the company.³⁰ While Dow argued that the results were unclear and that they did not wish to alarm workers unnecessarily, the company was nonetheless condemned for its refusal to act.³¹ These thirty-year-old genetic testing controversies only hint at the potential difficulties that may arise.

Current observers are uncertain of the impact these tests might have on the workplace. For example, Richard Lewontin argues that genetic screening would shift the onus of providing a safe workplace from the employer to the worker:

It becomes the worker's responsibility to look for work that is not threatening. After all, the employer is helping the workers by providing a free test of susceptibilities and so allowing them to make more informed choices of the work they would like to do. Whether other work is available at all, or worse paid, or more dangerous in other ways, or only in a distant place, or extremely unpleasant and debilitating is simply part of the conditions of the labour market.³²

Likewise, Bartha Maria Knoppers and Geneviève Cardinal warn that attributing disease to poor genes is an irresponsible error and that “[e]mphasizing the genetic aspect, while underestimating the effects of workplace hazards, has the potential to shift blame or responsibility from the employer to the employee.”³³ They worry “this shift of focus could even prove detrimental to ‘non-susceptible’ employees”.³⁴ Companies might feel justified in relaxing health standards to the limits of the law if they feel confident that they have hired only ‘normal employees’.³⁵ This shifted burden is indicative of the many foreseeable and unforeseeable dangers associated with genetic testing in the workplace.

Even without such a shift, a potential irony in using genetic testing to increase productivity and decrease costs in the workplace is that the opposite may instead occur. Discrimination based on a predictive, asymptomatic trait that may never come to pass effectively removes healthy and capable employees from the workforce. Lawrence Gostin argues that genetic discrimination “thwarts the creativity and productivity of human beings”.³⁶ Moreover, he

³⁰ *Ibid.*

³¹ *Ibid.* at 423.

³² *Supra* note 3 at 167.

³³ Bartha Maria Knoppers and Geneviève Cardinal, “Genetics and the Law” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds., *Canadian Health Law and Policy* (Toronto: Butterworths, 2002) at 454.

³⁴ *Ibid.* at 455.

³⁵ *Ibid.*

³⁶ Lawrence Gostin, “Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers” (1991) 17 *Am. J.L. & Med.* at 112.

suggests that to exclude these individuals deprives the workforce of “skills, energy and imagination.”³⁷ At the same time, a burden is placed on the already over-taxed welfare system when the Canadian people need not support a class of individuals who are fully capable, if permitted, of supporting themselves.

A wider concern is that the altruistic intent of the research will fail, as people will be hesitant to undergo tests due to worries that the information will be misused. In 1997, a national survey of 1 000 people in the United States, conducted by the federally-funded National Center for Genome Resources, found that nearly two-thirds of the respondents would not take a genetic test if employers and health insurers could see the results.³⁸ A related problem is that without people willing to participate in genetic research and submit themselves to genetic tests, it will be difficult for the science to advance and for cures to be developed. In effect, the possibility of genetic discrimination dissuades people from taking measures to catch disease at an early stage and hinders research into cures.

We cannot yet predict all of the consequences of introducing this new dynamic into the workforce. What is clear is that perspectives will shift—on the employer’s responsibilities, on the employee’s capabilities, on society’s faith in scientific advancement, and, most importantly, on how health and disability are regarded.

IV. PRIVACY PROTECTION

Having canvassed some of the potential dangers of genetic testing, I now turn to the means of preventing employer’s access to these tests and test results through privacy legislation. Privacy holds a revered, albeit amorphous, position in Canadian law. The Supreme Court of Canada has stressed that “[g]rounded in man’s physical and moral autonomy, privacy is essential for the well-being of the individual.”³⁹ As a consequence, the loudest voice against genetic testing has come from privacy advocates. A decade ago, the Federal Privacy Commission released a report concluding that there exists a right to genetic privacy and that employers must be prohibited from collecting genetic information.⁴⁰ More recently, the Commission has asserted:

The loss of autonomy and privacy can be the genesis of a life-long psychological prison—the prison of one’s perceived genetic programming...One’s reasonable

³⁷ *Ibid.* at 112, 113.

³⁸ Stephanie Armour, “Workers Fear Genetic Discrimination,” USA Today, Feb. 25, 1998 at 4B.

³⁹ *R. v. Dymnt*, [1988] 2 S.C.R. at 417, para 17.

⁴⁰ *Supra* note 15 at 111.

expectation of privacy can be violated by having others learn about one's genetic makeup. This loss of privacy can be debilitating. How others perceive us has a significant impact on our lives.⁴¹

Genetic testing of employees is tantamount to a bodily invasion, and clearly violates of our most basic notions of privacy.

A. Existing Privacy Legislation

A potential source of protection against public access to genetic information is offered through provincial privacy legislation. Some provinces have laws that establish a violation of privacy as an actionable tort.⁴² Privacy acts are, however, rarely invoked to protect against other means of testing already employed in the workplace and are unlikely to play a crucial role in protecting against the use of genetic tests.⁴³ Even the Federal Privacy Commission has warned, "Let no one be fooled; existing laws will not prevent realizing our worst fears about privacy abuses through genetic testing. Much more precise legal controls must be adopted."⁴⁴

Greater protection is found in certain parts of the country. Manitoba, Saskatchewan, Alberta and Quebec all have legislation that regulates the collection, use and disclosure of medical records including genetic records.⁴⁵ There is also federal legislation, the *Personal Information Protection and Electronic Documents Protection Act* ("PIPEDA")⁴⁶ that regulates the collection, use, and disclosure of personal information by commercial organizations that are federally regulated.⁴⁷ Personal health information was exempted from coverage until January 2002.⁴⁸ Now covered, personal health information encompasses genetic information as the definition includes "information derived from the

⁴¹ *Supra* note 21 at 4.

⁴² See for example, *Privacy Act*, R.S.B.C 1996, c.373, s.1.

⁴³ The legality of employer drug and alcohol testing policies is approached through human rights legislation. See *Entrop v. Imperial Oil Ltd.*, [2000] O.J. No. 2689 (C.A.)

⁴⁴ *Supra* note 21 at 3.

⁴⁵ Manitoba: *Personal Health Information Act* S.M. 1997, c. 51; Saskatchewan: *Health Information Protection Act* S.S. 1999, c. H-0.021; Alberta: *Health Information Act*, S.A. 1999, c. H-4.8b; Quebec: *An Act Respecting the Protection of Personal Information in the Private Sector*, R.S.Q. 1998, c.P-39.1

⁴⁶ *Personal Information Protection and Electronic Documents Protection Act*, S.C. 2000, c. 5 [hereinafter PIPEDA].

⁴⁷ *Ibid.*

⁴⁸ *Ibid.* at ss.30(1.1) and (2).

testing or examination of a body part or bodily substance of the individual".⁴⁹ Where provincial governments fail to enact similar data protection legislation governing provincially regulated commercial activities within three years of the Act coming into force, the PIPEDA extends to all commercial activity, both federal and provincial.⁵⁰ The legislation is nonetheless not a catch-all for complete genetic protection. In their analysis of the scope of privacy protection, Patrik Florencio and Erik Ramanathan conclude, "Although the PIPEDA is a step in the right direction, it inadequately protects information privacy and fails to address the issue of decision making privacy."⁵¹ Florencio and Ramanathan go on to propose the enactment of comprehensive privacy legislation as the best means to preserve privacy and prevent discrimination.⁵²

Yet, even if privacy legislation reaches a point of success where it can be considered to provide for the secure protection of individuals' genetic information, the possibility of employer access to a genetic record remains. There is nothing to stop an employer from making a test a precondition of employment or preventing information from being released voluntarily. Privacy legislation fails to provide any protection against subsequent misuse in these contexts.

V. GENETIC DISCRIMINATION

Accepting that employers will be able to access genetic information and then use it inappropriately, it is the responsibility of lawmakers to ensure that this information is not abused. There are two potential routes to this protection. The first is through the inclusion of genetic traits under the meaning of disability in the current scheme of anti-discrimination laws found in human rights legislation. The second is through the creation of separate genetic discrimination legislation. The remainder of this paper is devoted to the argument that the former is the superior route; the latter being both inappropriate and unnecessary.

A. Human Rights Legislation

Human rights codes prohibit discrimination on the basis of certain enumerated grounds. Determining whether a workplace standard violates a human rights code is a two-stage process. First, the workplace standard must be shown to be *prima facie* discriminatory on a prohibited ground. Secondly, once

⁴⁹ *Ibid.* at s.2.

⁵⁰ *Ibid.* at s.30(2).

⁵¹ *Supra* note 18 at 107.

⁵² PIPEDA, S.C. 2000, c. 5, s.79.

discrimination is established, the employer then has the burden to justify the standard. A standard is justifiable only if it is proven to be a *bona fide occupational requirement* ("BFOR"). The Supreme Court of Canada in *Ontario (Human Rights Commission) and O'Malley v. Simpson-Sears Ltd.* ("O'Malley") determined that a BFOR is established when the employer has accommodated to the point of undue hardship.⁵³ While initially a broad view of undue hardship was taken, the Supreme Court of Canada has recently issued a clear statement indicating the duty is rigorous. In *Meiorin*, the court created a three-part test that the employer must meet to justify a requirement:

Was the standard adopted for a purpose rationally connected to the performance of the job;

Did the employer adopt the particular standard in an honest and good faith belief that it was necessary to the fulfilment of the legitimate work related purpose; and

Is the standard reasonably necessary to the accomplishment of that legitimate work related purpose? In order to show that the standard is reasonably necessary, it must be demonstrated that it is impossible to accommodate individual employees sharing the characteristic of the aggrieved employee without imposing undue hardship upon the employer.⁵⁴

While human rights codes cannot prevent all discriminatory acts of employers, they do constrain an employer from action unless a BFOR is demonstrated. To receive this protection, however, genetic discrimination must fall within one of the prohibited grounds.

B. Genetic Discrimination

As it encompasses a range of possibilities, the meaning of "genetic discrimination" is more difficult to define than other areas of discrimination such as sex or race. It has been defined in the literature variously as:

"differential treatment based on genetic status"⁵⁵

"the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests"⁵⁶

⁵³ *Ontario (Human Rights Commission) and O'Malley v. Simpson-Sears Ltd.* [1985] 2 S.C.R. 536 at para 23 [hereinafter *O'Malley*].

⁵⁴ *Supra* note 19 at 24-25.

⁵⁵ Mark Rothstein "Genetic Discrimination in Employment: Ethics, Policy and Comparative Law" in Swiss Institute of Comparative Law, ed., *Human Genetic Analysis and the Protection of Personality and Privacy* (Zürich: Schulthess Polygraphischer Verlag, 1994) 129 at 129 qtd. in Lemmens *supra* note 7 at para 15.

⁵⁶ Gostin, *supra* note 33 at 110.

“discrimination against an individual or against members of that individual’s family solely because of real or perceived differences from the ‘normal’⁵⁷ genome of that individual” as distinguished from “discrimination based on disabilities caused by altered genes”⁵⁸

“the use of genetic information about an asymptomatic person.”⁵⁹

Notwithstanding definitional debate, the international community has recognized the possibility of genetic discrimination. The World Medical Association in 1992 issued a *Declaration on the Human Genome Project*, suggesting, “It may be desirable, regarding genetic factors, to adopt the same tacit consensus which prohibits the use of race discrimination in employment or insurance.”⁶⁰ In anticipation of the Human Genome Project’s completion, UNESCO passed a *Universal Declaration on the Human Genome and Human Rights* in 1997 (“*Universal Declaration*”).⁶¹ The *Universal Declaration* states, “No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.”⁶² More recently, the Council of Europe’s 1997 *Convention on Human Rights and Biomedicine* (“*Convention*”)⁶³ received sufficient ratification to come into force.⁶⁴ The *Convention* bans all forms of discrimination based on a person’s genetic make-up and allows the carrying out of predictive genetic tests only for medical purposes. The *Convention* also sets out rules for medical research and recognizes a patient’s right not to know.⁶⁵ Thus, while

⁵⁷ Paul Billings et al., “Discrimination as a Consequence of Genetic Testing” (1992) 50 Am. J. Hum. Genet. 476 qtd. in Lemmens *supra* note 7 at para 15.

⁵⁸ *Ibid.*

⁵⁹ M.S. Yesley, “Protecting Genetic Difference” (1999) 13 Berkeley Tech. L.J. 653 at 662 qtd. in Lemmens *supra* note 7 at para 15.

⁶⁰ World Medical Association, 44th Assem., World Medical Association Declaration on the Human Genome Project, Doc. 17 S/1 (1992).

⁶¹ Universal Declaration on the Human Genome and Human Rights, UNESCO, 29th Sess., 29 C/Resolution 19 (1997).

⁶² *Ibid.* at 6.

⁶³ Council of Europe, *Convention on Human Rights and Biomedicine* ETS No. 164; online: <http://conventions.coe.int/Treaty/EN/CadreListeTraites.htm> (accessed November 16, 2003).

⁶⁴ The Convention entered into force on 1st December 1999 in Denmark, Greece, San Marino, Slovakia and Slovenia (the first five states having ratified it).

⁶⁵ While the convention theoretically offers comprehensive protection against genetic discrimination, Canada, although having participated in the development of the *Convention*, has yet to sign or ratify the treaty.

genetic discrimination has yet to reach the Canadian workforce, such international attention clearly signifies that it is an evolving issue that must be approached with concern.

In the employment context, the key to defining genetic discrimination is that the discrimination is based on a predictive or asymptomatic genetic marker that does not affect the current abilities of the employee. With this definition, there is no actual disability but only the future potential for disability. Once symptoms are manifest, the individual will clearly fall within the normal scope of mental or physical disability protected by existing human rights legislation. The question is whether individuals can and should be included under the ground of disability prior to the manifestation of their symptoms. In essence, is it appropriate for healthy persons, many of whom will never become ill, to receive protection from genetic discrimination on the ground of disability?

C. Coverage Under Disability

There is a fear that protection against discrimination in human rights statutes is becoming an abyss into which almost anything can be thrown and that the original intent of the legislation is being forgotten. Genetic markers do not, however, fall into the category of labels that challenge the legislative purpose. Human rights law developed to protect the historically disadvantaged.⁶⁶ Discrimination against the genetically unfit is not a new creation of our scientific era, rather only the scope of its visibility has been widened by recent research. Tay-Sachs disease, for example, is known to be common among Ashkenazi Jews and some French Canadians. Africans and those of African origin have a high incidence of the sickle-cell trait. As the Du Pont example above demonstrated, this latter genetic tendency led to the discrimination of African Americans as far back as the 1970s where, in the United States, widespread sickle-cell screening was introduced on the faulty premise that exposure to low oxygen levels put carriers at risk of losing consciousness. As a protective measure, many African Americans identified as carrying the trait were then excluded from certain occupational settings.⁶⁷ This highlights another aspect of genetic discrimination: the predominance of certain genetic traits in specific groups may foster discrimination on the basis of race, ethnicity or gender. To argue, therefore, for the extension of disability coverage to encompass predictive genetic traits is, I conclude, not an abuse of the ground.

To date, no case of genetic discrimination has come before a Canadian court. The Canadian Human Rights Act Review Panel has concluded that the

⁶⁶ See *Eldridge v. B.C. (Attorney General)*, [1997] 3 S.C.R. at 624, para 54.

⁶⁷ D.J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (New York: Alfred A. Knopf, 1985) 255–256 at 278.

*Canadian Human Rights Act*⁶⁸ is currently unclear on whether protection would extend to situations where a test result indicates a predisposition to a disability but the disability has not, and may never, become manifest.⁶⁹ The closest Canadian example is that of *Audet v. Industrielle-Alliance, Cie d'Assurance Sur la Vie* (“*Audet*”).⁷⁰ In *Audet*, a Quebec widow was denied her husband’s life insurance payment. Her husband had volunteered to participate in a research project where he was found to have a positive presymptomatic electromyographic test that is usually associated with Steinert’s disease (myotonic dystrophy). Although he died in a car crash and not of the “disease”, the court, agreeing with the insurance company, found that he had not disclosed all pertinent medical information concerning his “diseased” status and thereby forfeited his insurance coverage.

The Supreme Court of Canada has however encountered the issue of *perceived* disability within a different context. *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*, (“*Boisbriand*”) involved three cases (Mercier, Hamon and Troilo) where employees or applicants for employment were denied employment on the basis of physical anomalies that did not result in physical limitations for the purposes of employment.⁷¹ At issue were Quebec’s *Charter of Human Rights and Freedoms* (“*Charter*”) and whether these anomalies could be considered a “handicap” within the meaning of s.10 of the Quebec Charter.⁷² Madame Justice L’Heureux-Dubé, speaking for a unanimous court, held that there must be a large and purposive definition of handicap.⁷³ As a consequence she was of the view that “the Charter’s objective of prohibiting discrimination requires that “handicap” be interpreted so as to recognize its subjective component. A “handicap,” therefore, includes ailments which do not in fact give rise to any limitation or functional disability.”⁷⁴ She

⁶⁸ *Canadian Human Rights Act*, R.S.C. 1985, c.H-6.

⁶⁹ The Canadian Human Rights Act Review Panel, *Promoting Equality: A New Vision*, Report (Ottawa: The Canadian Human Rights Act Review Panel, 2000) ch.17(a).

⁷⁰ *Audet v. Industrielle-Alliance, Cie d'Assurance Sur la Vie* [1990] R.R.A. 500-502 (C.S.).

⁷¹ *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Boisbriand (City)*, [2001] 1 S.C.R. 665

⁷² *Charter of Human Rights and Freedoms*, R.S.Q., c. C-12. While the Quebec Charter uses the term “handicap”, the ruling can be read to cover other human rights statutes that use the term “disability.” L’Heureux-Dubé J. noted that “[t]his Court has often stressed that mere differences in terminology do not support a conclusion that there are fundamental differences in the objectives of human rights statutes.” *Supra* note 66 at para 46. Thus, for the purposes of this paper, the terms “disability” and “handicap” are used interchangeably.

⁷³ *Supra* note 66 at paras 26-29, 71.

⁷⁴ *Ibid.* at para 41.

then noted the inclusion of perception in the definition, stating, that “it is clear that “handicap” as it is used in the Charter can include both an ailment, even one with no resulting functional limitation, as well as the perception of such an ailment.”⁷⁵ Her reasoning being that “the emphasis is on the effects of the distinction, exclusion or preference rather than the precise nature of the handicap, the cause and origin of the handicap are immaterial.”⁷⁶ Thus, the test for disability coverage as set forth in her reasons is whether an actual or perceived ailment causes the individual to experience ‘the loss or limitation of opportunities to take part in the life of the community on an equal level with others’⁷⁷ Madame Justice L’Heureux-Dubé reasoning was premised upon the fact that “discriminatory acts may be based as much on perception and myths and stereotypes as on the existence of actual functional limitations.”⁷⁸ An individual’s actual ability to perform job duties is contrasted with the employer’s “subjective and erroneous perceptions regarding the existence of such limitations.”⁷⁹

The issue in genetic discrimination is different. The employer’s concern with genetic markers is that there will be a future functional limitation that will either cause the employer to lose the employee and thereby suffer the associated costs of additional training or of accommodating the employee. The employer in this context is not concerned with the employee’s current capabilities; instead, the employer is concerned only with a future possibility of disability. Employers are discriminating to pre-empt the issue of disability. The reasoning in *Boisbriand* does not, therefore, suggest that genetic discrimination must be protected against under the disability or handicap ground in human rights legislation. Nevertheless, while L’Heureux-Dubé J.’s analysis focused on perception, the motivating forces behind the discriminations at issue were potential future disabilities. In *Mercier*, the complainant was refused employment as a gardener-horticulturist because the City was concerned that she would develop lower back pain due to a minor thoracolumbar scoliosis (an anomaly in her spinal column) even though she had never suffered any lower back pain or had a serious injury. The *Hamon* case likewise concerned a complainant who was not hired as a police officer because of anomalies to his spinal column. *Troilo* involved a complainant with Crohn’s disease (a chronic

⁷⁵ *Supra* note 66 at para 72. Ontario and Nova Scotia both specifically reference perception in their definitions of “disability.” See *Human Rights Code*, R.S.O. 1990, c.H.19, s.10(3); *Human Rights Act*, R.S.N.S. 1989, c.214, s.3(1).

⁷⁶ *Ibid.* at para 81.

⁷⁷ *Ibid.* at para 80.

⁷⁸ *Supra* note 66 at para 39.

⁷⁹ *Ibid.* at para 48.

inflammation of the intestine) who was dismissed from his employment as a police officer despite medical reports attesting to his good health and the fact that he was asymptomatic.⁸⁰ The employers' perceptions clearly centred on future concerns instead of current inabilities. Still, the individuals considered in *Boisbriand* did in fact fall within some vague categorization of difference in that they had identifiable, manifested 'problems'. Arguably, L'Heureux-Dubé J.'s reasoning may not extend to *potential future ailments* of individuals who are currently in 'perfect' health.

There is no reason, however, not to permit her reasons this extended reach. Madame Justice L'Heureux-Dubé stressed the need to give human rights legislation a liberal and purposive interpretation.⁸¹ She reasoned:

The purpose of Canadian human rights legislation is to protect against discrimination and to guarantee rights and freedoms. With respect to employment, its more specific objective is to eliminate exclusion that is arbitrary and based on preconceived ideas concerning personal characteristics which, when the duty to accommodate is taken into account, do not affect a person's ability to do a job.⁸²

Discrimination based on genetic markers fits this purpose as it is discrimination concerning personal characteristics that do not affect a person's ability to do a job. Moreover, refusing to narrowly confine her concept of handicap, L'Heureux-Dubé J. concluded her judgment by recognizing that notions of disability are changing as a result of scientific advancements:

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 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 today may or may not be one tomorrow, an overly narrow definition would not necessarily serve the purpose of the Charter in this regard. [emphasis added]⁸³

As a final comment, not elaborated upon elsewhere in the judgment, she adds, "Further, the Charter also prohibits discrimination based on the actual or perceived *possibility* that an individual may develop a handicap in the future."⁸⁴ Taken together, these last two comments clearly suggest that L'Heureux-Dubé J. has anticipated that the next interpretation of 'disability' or 'handicap' will

⁸⁰ *Ibid.* at para 3. The Troilo case is somewhat different as the complainant had been absent for a period of time because of an acute attack of ileitis followed by a fistula (perforation of the intestine), which was treated surgically.

⁸¹ *Ibid.* at paras 26–29, 71.

⁸² *Supra* note 66 at para 36.

⁸³ *Ibid.* at para 76.

⁸⁴ *Ibid.* at para 81. [emphasis added]

include genetic predispositions or markers. Her reasoning indicates that such an expanded interpretation is appropriate. The Canadian Human Rights Act Review Panel reached the same conclusion and has recommended that, "the definition of "disability" in the Act should include the predisposition to being disabled."⁸⁵

As the question of coverage for perceived genetic disabilities is already at the forefront of debate in the United States,⁸⁶ it is appropriate to turn briefly to the American discussion, if only to argue that it should be read with caution. The American discussion is heading in the opposite direction of *Boisbriand*, and L'Heureux-Dubé J.'s reasons appear to have precluded Canada from following suit. Under s. 12102(2) of the *Americans with Disabilities Act* ("ADA"), a person with a disability is a person who:

has a physical or mental impairment that substantially limits one or more major life activities; has a record of such an impairment; or is regarded as having such an impairment.⁸⁷

While there is an argument that persons with asymptomatic genetic markers could fit within the first category of this test,⁸⁸ the more viable argument lies under the third category. This third category echoes L'Heureux-Dubé J.'s comments in *Boisbriand* and reflects the acknowledgement that "society's accumulated myths and fears about disability and disease are as handicapping as are the physical limitations that flow from actual impairment."⁸⁹ It is here that the U.S. Equal Employment Opportunity Commission ("EEOC") determined in 1995 that the ADA prohibits discrimination against workers based on their genetic make-up.⁹⁰ The EEOC, however, offers only guidelines and holds no legal power of enforcement. Entitled only to judicial deference, the case law does not at all times reflect the EEOC view.⁹¹

⁸⁵ *Supra* note 64, rec.119.

⁸⁶ Mark Rothstein, "Genetic Privacy and Confidentiality: Why They Are So Hard to Protect" (1998) 26 J.L. Med. & Ethics 198 at 201. A listing of enacted American legislation on genetic information can be found at <http://www.genome.gov/10002338> (accessed November 16, 2003).

⁸⁷ *Americans with Disabilities Act*, 1990, 104 Stat. 328, 42 U.S.C. section 12102(2).

⁸⁸ See Gridley, *supra* note 4 at 984. Gridley looks at *Bragdon v. Abbott* 524 U.S. 624 (1998) where the U.S. Supreme Court held that a person infected with presymptomatic HIV has a physical impairment that "substantially limits" reproduction, which the Court deemed a major life activity, and therefore HIV constitutes a disability under the ADA. She argues that by analogy some genetic impairments could likewise fit within this requirement.

⁸⁹ *School Board of Nassau City v. Arline*, 480 U.S. 273 at 284 (1987).

⁹⁰ EEOC Compliance Manual (CCH), at 902 (Mar. 14, 1995).

⁹¹ Gridley, *supra* note 4 at 992.

In *Sutton v. United Airlines* (“*Sutton*”) the U.S. Supreme Court refused to follow the EEOC guidelines and held that an employee’s disability should be considered in its unmitigated state in determining whether it is substantially limiting.⁹² While the dissent turned back to Senate discussions on the third category and cited the Senate’s statement that:

[An] important goal of the third prong of the [disability] definition is to ensure that persons with medical conditions that are under control, and that therefore do not currently limit major life activities, are not discriminated against on the basis of their medical conditions. For example, individuals with controlled diabetes or epilepsy are often denied jobs for which they are qualified. Such denials are the result of negative attitudes and misinformation.⁹³

The third category of the ADA was essentially glossed over and ignored by the majority judgment. Justice O’Connor concluded that eyesight impairment did not substantially limit a major life activity in preventing access to a broad range of employment but only to the specific position of a commercial airline pilot. As a consequence it was held that:

[an] employer is free to decide that physical characteristics or medical conditions that do not rise to level of an impairment such as one’s height, build, or singing voice are preferable to others, just as it is free to decide that some limiting, but not substantially limiting, impairments make individuals less than ideally suited for a job.⁹⁴

This reasoning can be made sense of only by rationalizing that the case concerned severe myopia and the Court was hesitant to suggest that glasses could be considered a disability. From the Canadian perspective, the ruling is particularly disturbing as the American legislation seems to extend much further than its Canadian counter-parts in providing coverage for perceived disability, and yet the Court nevertheless denied protection. If there is a reluctance to extend coverage to those who wear glasses, it seems even more probable that a court would be hesitant to allow coverage to healthy individuals with only a heightened likelihood of becoming ill, at an unknown time in the future.

The first court action challenging the use of genetic testing under the ADA was initiated by the EEOC against the Burlington Northern Santa Fe Railroad (“BNSF”). BNSF required employees claiming carpal tunnel syndrome to submit to screenings for a genetic disposition to the condition. The case was settled out of court in spring 2001.⁹⁵ The EEOC continued to investigate

⁹² *Sutton v. United Airlines*, 527 US 471 (1999).

⁹³ *Ibid.* at para 62.

⁹⁴ *Ibid.* at para 42.

⁹⁵ *The U.S. Equal Employment Opportunity Commission* press release 18 April 2001, online: <http://www.eeoc.gov/press/4-18-01.html> (accessed November 16, 2003).

separate charges that BNSF discriminated against one of the workers by threatening to fire him.⁹⁶ A court ruling in this, or a similar, case will offer the first statement on whether genetic discrimination is covered under the ADA. Should the decision follow *Sutton*, it should not be presumed to apply in Canada. *Boisbriand*, while not yet explicitly recognizing protection against genetic discrimination, has at least negated the possibility of following the American analysis.

D. Alternative Coverage

The alternative to expanding the scope of disability coverage is to create separate gene-focused legislation. This proposal is the subject of some controversy. Knoppers and Cardinal argue that existing legislation is not sufficient to handle these issues and that protections must be tailored to the specific problems that arise with genetic testing in the employment context.⁹⁷ The Standing Committee on Human Rights and the Status of Persons with Disabilities supported separate legislation in light of the unique nature of genetic traits. For the Committee, the distinguishing factor was that genetic tests affect not only the individual tested but also the individual's family and family members could be affected by results of tests with which they were in no way involved. The Committee concluded, "Canada needs very separate and special protections to regulate the collection, use and ownership of genetic information because of its very private, personal nature and its potential intrusiveness."⁹⁸

The proposal for separate legislation is countered by Lemmens who argues that, "singling out genetic susceptibility as a category, and offering it much wider protection than other similar health conditions, although intended to promote equity in access to social goods, may themselves be ineffective and to some extent even inequitable."⁹⁹ Beckwith and Alper highlight such unfairness through the following example: that one employee is found to carry a gene conferring susceptibility to colon cancer but who is not presently affected by the disease; another individual has a non-genetic clinical test indicating a pre-cancerous condition that sometimes leads to colon cancer. Both men may be at equal risk for the cancer but the former would be protected through genetic

⁹⁶ Online Newshour, June 7, 2001, online: http://www.pbs.org/newshour/bb/health/jan-june01/genetest_06-07.html (accessed November 16, 2003).

⁹⁷ *Supra* note 32 at 457.

⁹⁸ Standing Committee on Human Rights and the Status of Persons with Disabilities, The Third Report to the House, Recommendation 14: online:http://www.parl.gc.ca/committees352/huso/reports/03_1997-04/chap4e.html (accessed November 16, 2003).

⁹⁹ *Supra* note 7 at para 2.

anti-discrimination legislation while the latter would find no legislative protection.¹⁰⁰ The Canadian Human Rights Act Review Panel likewise recognized that “[t]hough this concern especially arises with genetic analysis, it is also true of other conditions. For example, a person may be HIV positive, yet not have any symptoms of AIDS. It could be the same for multiple sclerosis.”¹⁰¹ Even Knoppers and Cardinal acknowledge that gene-specific legislation may facilitate a ‘stigmatization’ of genetic conditions and, “undermine the gradual ‘normalization’ of genetic conditions by singling them out from medical conditions generally.”¹⁰²

A further problem is the inability to distinguish genetic and non-genetic tests. Beckwith and Alper point out that “most medical tests are ordered in an effort to detect conditions or potential conditions that have an underlying genetic contribution.”¹⁰³ In another article they write that “in concentrating on the genetic nature of the information rather than on the consequences of the dissemination of all types of medical information, the [genetic anti-discrimination] legislation relies on a distinction between genetic and non-genetic information that is essentially artificial.”¹⁰⁴ Definitional issues come into play—Beckwith and Alper point out that genetic discrimination may be limited to information on the actual genetic material (DNA and RNA), extend to include proteins whose synthesis is directed by genes, or even stretch to include information based on family history.¹⁰⁵ They refer to a proposed California bill that would “prevent employers from using genetic information based on conjectures from someone’s appearance or ethnicity”.¹⁰⁶

Beckwith and Alper do not propose, however, that no new legislation is required. Rather, they advocate anti-discrimination legislation be written to prohibit discrimination on any predictive medical information.¹⁰⁷ They are writing from an American viewpoint tainted by the inadequate development of the law in cases such as *Sutton*. In Canada, their proposals could be accomplished through an amendment to current human rights statutes so that discrimination on the basis of disability would include “potential disability” or a

¹⁰⁰ *Supra* note 18 at 207–208.

¹⁰¹ *Supra* note 64 at ch.17(a).

¹⁰² *Supra* note 32 at 458.

¹⁰³ *Supra* note 18 at 207.

¹⁰⁴ *Supra* note 8 at 145.

¹⁰⁵ *Supra* note 18 at 207.

¹⁰⁶ *Ibid.*

¹⁰⁷ *Ibid.*

“predisposition to being disabled”, as the Canadian Human Rights Act Review Panel recommended to Parliament. Even without such amendments, L’Heureux-Dubé J.’s comments in *Boisbriand* suggest that current legislation can be read to include protection against genetic discrimination. Either approach is in line with the flexibility advocated in *Boisbriand*. As L’Heureux-Dubé J. indicated:

This is not to say that the biomedical basis of “handicap” should be ignored, but rather to point out that, for the purposes of the Charter, we must go beyond this single criterion. Instead, a multi-dimensional approach that includes a socio-political dimension is particularly appropriate.¹⁰⁸

New gene-specific legislation is superfluous, potentially dangerous, and impossible to define. The better approach is to find protection in our human rights codes. The Supreme Court did not hesitate to read perception into the definition “handicap”; reading in predispositions can also be justified.

VI. CONCLUSION

When scientists perceived themselves as Arthurian knights and alluded to the genome as the modern grail of human identity, they were still immersed in the frenzied race to succeed in the quest. With the sequence now complete, Lewontin points out that “we do not, alas, know anything more than we did before about what it is to be human.”¹⁰⁹ While the genome may not provide this answer, it does serve to pose the question: what does it mean to be human. Our answer will be determined by how we choose to use this new information. Employment is merely one of many areas that will be affected by the advancement of genetic science. In all areas, what is at stake is our perception of ourselves. Human rights statutes exist to protect dignity and ensure fair and equal treatment. When science turns to science fiction, the result is almost always a horror. When the fiction turns to science, let us hope that we prove stronger.

¹⁰⁸ *Supra* note 66 at para 77.

¹⁰⁹ *Supra* note 3 at 189.

