GENETIC DETERMINISM AND DISCRIMINATION: A CALL TO RE-ORIENT PREVAILING HUMAN RIGHTS DISCOURSE TO BETTER COMPORT WITH THE PUBLIC IMPLICATIONS OF INDIVIDUAL GENETIC TESTING

ABSTRACT

Genetic testing can not only provide information about diseases but also respecting their prevalence in ethnic, gender or other vulnerable populations. While offering the promise of significant therapeutic benefits and serving to highlight our commonality, genetic information also raises a number of sensitive human rights issues touching on identity and the perception thereof, as well as the possibility of discrimination and social stigma. Moreover, the stoicism with which the public tends to greet such data is of particular relevance to its eventual impact on rights in the genomics age. It stands to reason that the results of individual screenings could haplessly be used to make *general* assumptions about entire ethic or gender groups. In this manner, genetic information can directly influence identity impacting and perhaps even reframing conceptions of group rights and dimensions of self-identification, thus importing constitutional scrutiny on questions of dignity and discrimination in particular. Is there a risk of collective stigmatization deriving from discrete testing of self-identified individuals? Would such stigmatization impinge on individual dignity by the exogenous imposition of ethnic or gender/sexual identity? If so what norms can most adequately respond if and when individual and group interests diverge? These questions will be examined from a Canadian and comparative perspective.

KAREN ELTIS

Professor Karen Eltis is a member of the Faculty of Law at the University of Ottawa, specializing in comparative constitutional law, democratic governance and transnational legal problems, with a particular interest in new technologies. She is the immediate past Director of the Human Rights Research and Education Centre (Ottawa) and Co-Director of the National Program, the Law Faculty's bijuridical graduate program.

"Privacy considerations no longer arise out of particular individual problems; rather, they express conflicts affecting everyone." [1]

Along with the promise of assuaging the scourge of disease, the so-called genetic revolution unquestioningly imports a slew of thorny human rights issues that touch on matters such as dignity, disclosure, and the subject of this article – genetic testing and the social stigma potentially deriving therefrom.

It is now rather evident that certain otherwise therapeutically promising forms of research can inadvertently involve social risks exceeding the individual preoccupations of eclectic study participants.[2] With that being the case, the following proposes to examine the peculiar stigma attached to genetic information and its potential human rights implications extending beyond the insurance and employment context. In so doing, it raises the intersection of interests between self-identified members of historically vulnerable groups and the group itself, which the law seems to take for granted in the genetics context. While this paper purports to offer no more that an initial reflection on point, its immediate objective is to expand the examination of human rights issues arising from individual genetic testing to include the potential ramifications for vulnerable groups, which may be adversely affected by such research findings and bio-banking in the larger sense.[3]

While human rights scholarship has traditionally centered on individual civil liberties,[4] the rapid emergence and radical progression of biotechnology, genetic research in particular, may well prompt us to reorient – or at the very least revisit – human rights discourse. More specifically, it stands to reason that the results of individual screenings could haplessly be used to make *general* unintended assumptions about entire ethnic or gender groups, thus compelling a re-examination of individually-oriented human rights mechanisms. For instance, in fall 2005, a local psychiatrist **caused** a stir in Montreal when he declared on a popular radio talk show that people of color were somehow *innately* – or genetically programmed to be – less intelligent.[5] Quite significantly, he hoisted the shield of science in defense of his unpalatable assertions.[6]

Arguably similar in certain respects, a scientific paper published in the *Journal of Biosocial Science*,[7] not only suggests that one group of humanity is more intelligent than others, but explains the genetic process that supposedly brought this about. The group is Ashkenazi Jews. The process is natural selection, and the article discusses a dozen or so disease genes that are common in Ashkenazi Jews and their purported role in this intelligence process. While seemingly complimentary at first glance, anyone even moderately familiar with Jewish history can immediately grasp how contentions such as these (respecting ostensible Jewish exceptionality or "genius") can prove a breeding ground for racism (reminiscent of eugenics[8]).[9]

Harvard University's embattled former president, Lawrence H. Summers, is no exception, as he too was the target of vociferous attacks and calls for resignation[10] following comments he made suggesting that innate genetic differences between the sexes may be one explanation for why fewer women succeed in careers in math and science. In the same vein, the comments are a source of particular unease by reason of their purported scientific justification.[11]

These incidents and others unequivocally highlight the growing impact of emerging genomics on traditional human rights discourse and protective mechanisms. As a comparative survey of the Canadian and American normative framework undertaken herein reveals, traditional human rights theory and instruments may not lend themselves particularly well to the radical changes occasioned by genomic science. Indeed, the above-cited example respecting the purported "intelligence" of certain cohorts illustrates how the results of individual screenings could be used to make *general* assumptions about entire ethnic or gender groups.[12] The *public* human rights ramifications of genetic information are becoming impracticable to ignore,[13] yet the individualistic orientation adopted by the tools for their promotion and protection subsist.

Tellingly, while the debate among jurists on point has for the most part focused on whether genetic information is an *exceptional* form of *personal* information,[14] warranting separate normative treatment, it has done so almost exclusively in the insurance[15] and employment[16] – specifically, from the perspective of the individual subjected to genetic screening.[17] But what of persons belonging to what the Supreme Court of Canada refers to as "historically vulnerable groups"?[18] Curiously, the *social*[19] human rights implications of ethnicity through the prism of genomic knowledge have been the object of little scrutiny.[20]

Notwithstanding, it bears repeating that some forms of research may carry risks of public import[21] extending far beyond the individuals[22] undergoing genetic testing,[23] particularly when these individuals belong – or are externally perceived as belonging – to a vulnerable gender or ethnic group.[24]

To complicate matters even further, personal and group interests may quite plausibly diverge in the genetic context, thus shattering the oft-presumed intersection of interests between a minority group member and her community that the law seems to take for granted.[25] We need look no further for an example than the BRCA gene controversy,[26] whereby certain individual Jewish women may wish to be tested for the gene, whereas at the same time, Jewish women as a community are increasingly voicing concern over the stigma of the "Jewish breast cancer gene"[27] and its collective implications.[28]

This is the dilemma of *intersectionalities*[29] that the law pertaining to discrimination must struggle to address in the area of genetics.[30] Conceived from this angle, even the proposed "therapeutic-benefit test,"[31] which advocates genetic testing only if it offers health benefits to the subject, may be of little use since while individual may indeed profit,[32] the test results may eventually serve to promote harmful stereotypes of the group with which the tested person is associated – even though he may not self-identify with the cohort in question.[33]

One such example – arguably most pressing to inspect from a human rights perspective – is the study of behavioral propensities (most notably susceptibility to violence)[34] as they intersect with ethnicity.[35] As shall be further discussed in Part II, scientists have already uncovered "neural mechanisms of genetic risk for impulsivity and violence in humans." [36]

While it is beyond the scope of this present endeavor to fully flesh out these multiple and highly complex issues, the implications for human rights both within and without criminal justice are staggering, particularly when we are reminded that the very term "race" was coined in the context of "scientific" research.[37] If "the harms of racially targeted testing extend beyond the individual to entire social groups" as Lee *et al*. suggest,[38] can even *distinctive* statutory vehicles fashioned within "our current, individually focused system for protecting human subjects in research… provide adequate protection" from the *public* consequences of genetic testing?[39]

My purpose here again is to spark preliminary reflection on this very matter, past the prevailing individualistic privacy discourse. Cognizant of the value and tremendous potential of genetic research, I will attempt to revisit the legal analysis of genetic testing in terms of human rights, in an effort to highlight the potential risk of discrimination that biobanking may inadvertently have upon ethnic or other vulnerable groups and the need to adjust individually-oriented human rights theory accordingly. By endeavoring to *reframe* the legal debate surrounding genetics – now focusing primarily, if not exclusively, on personal information in the employment and insurance context – with a view to realigning legal discourse with the imperatives of remarkable scientific advances, this initial reflection serves as a prelude to rethinking the relevant normative framework in light of the leveled critiques. From a human rights perspective, such an approach would recognize the *multiplicity of interests* at stake and the interplay of intersectionalities in order to promote more informed policy decisions.

To sum up the predicament addressed in this article: First, as discussed in Part I, which summarily exposes the relevant *Charter* provisions, the debate is almost entirely confined to the employment/insurance ramifications of genetic discrimination.[40] Secondly, the law generally assumes identity of interest between an individual and his or her social group, and thirdly, it seems to disregard the stoicism[41] with which the public tends to greet scientific data,[42] and the media's oftentimes simplistic presentation thereof as addressed in Part II. Finally Part III sets forth a number of preliminary recommendations aimed at forming the basis for addressing the leveled critiques.

Part I

With an eye towards igniting debate on these pressing questions, this article will first briefly review the *Charter* framework relevant to the protection of human rights in the genetics context in Canada. As conducting a thorough normative survey would be beyond the scope of this undertaking, the following concise *apercu* is tendered with the sole intention of highlighting the law's seeming single-minded focus on the individual ramifications of genetic information and its consequent insufficiency from a human rights perspective.

Individual rights

In contradistinction to what appears to characterize the American experience at the state level,[43] many Western democracies have chosen not to recognize "genetic exceptionality,"[44] preferring instead to let the traditional juridical mechanisms pertaining to personal information govern the matter. Regardless of the approach, such data has been construed primarily through the optic of *personal privacy* rather than dignity,[45] which follow the individualized approach.

Canada is no exception, having to date refrained from crafting any distinctive legislative vehicle to deal with genetic information[46] (apart from legislation dealing specifically with the use of DNA in criminal investigations and those relating strictly to reproductive technologies).[47] Instead, most provisions relevant to genetic discrimination are found in general norms drafted in abstract of genetics and often long prior to the so called "genetic revolution." Chief amongst these is Canada's constitutional law, data protection (privacy protecting measures) instruments, and human rights statutes. According to this approach, genetic discrimination can be dealt with under the normative structure designed for personal information and privacy generally. A closer look is mandated at this juncture.

The *Canadian Charter of Rights and Freedoms* offers some measure of protection for personal information from government intrusions. Based on the ICCPR, the *Charter* is an individualistic

document, whose focus is on individual – rather than collective rights – as much as it is on state rather than private infringements thereupon.[48] For our purposes, this document is most significant in light of the potential public or group implications of genetic testing – problems the *Charter* may be ill-equipped to address.

While *Charter* protections of personal information and privacy are by no means explicit (nor do they specifically pertain to genetic or even health information), the *Charter* is deemed a "living tree," able to evolve with the imperatives of the time, including advances in science and technology.

Therefore, while privacy is not actually an enshrined Charter value, privacy principles are gleaned from *Charter* jurisprudence, the most relevant provisions being s.7, liberty and security of the person and s.8, freedom from unreasonable search and seizure. While the right to privacy has been crowned the most natural casualty of improper genetic testing, it stands to reason that the social implications deriving therefrom are liable to affect group rights, most notably equality and dignity.

Arguably then, an equally pertinent *Charter* value relevant to the present context is section 15(1), which protects against prohibited discrimination and is said to be predicated on human dignity. It is precisely the dignity-based rationale that may best comport with the protection of sensitive information pertaining to group defamation. Particularly since in the leading case of *Law v. Canada* (Minister of Employment and Immigration) where the dignity prong of the equality test was set forth, the Supreme Court of Canada seemed to make a rare reference to group rights, declaring:[49] "Human dignity is harmed when individuals *and groups* are marginalized, ignored, or devalued, and is enhanced when laws recognize the full place of all individuals and groups within Canadian society." (Emphasis added.) In a word, therefore, discrimination is to be assessed from the optic of dignity.

A few caveats: Here again, identity of interests between the individual and group is simply presumed. Furthermore, *Charter* rights are not absolute but may be reasonably violated, provided that the infringement is proportionally justified as per section 1 of the Charter (evaluated using the Oakes test). More importantly perhaps, only discrimination at the hands of government is constitutionally proscribed.

However, because *Charter* values are said to permeate the law's understanding of private dealings, the *Canadian Charter's* values must infuse the interpretation of all legislation, particularly provincial human rights codes.

Human rights instruments

While the *Charter's* own application to the private realm is at best indirect, provincial human rights instruments *explicitly* govern private dealings. Chief amongst them is the Quebec *Charter*, which unlike its counterparts is a document of quasi-constitutional stature. Moreover, in contradistinction to the *Canadian Charter*, the Quebec *Charter* offers explicit protection for privacy, equality and dignity.

Part II

While specific attention is rarely given to genetic information, any focus appears to be on the employment and insurance context. Remarkably, however, the question of the social implications of genetic discrimination has gone largely unconsidered by lawmakers and jurists in both countries.

In other words, while the U.S. has chosen to specifically legislate at the state level and Canada has not, both focus on employment and insurance from an individual perspective. Moreover, genetic discrimination seems to be construed through the prism of personal privacy. Nevertheless, it may in fact hold significant collective implications, as it gradually relates to defined ethnic groups. This shift may in turn invite us to revisit – perhaps even reframe – the debate.

Plainly put, while genetic information may very well resemble other forms of predictive health data for purposes of insurance and employment, its public ramifications, specifically its impact on popular understanding, or misunderstanding of race and ethnicity, appears rather distinctive and is therefore meritorious of closer examination.

The peculiarity of scientific data

To paraphrase Irwin Cotler that if science is indeed the "secular religion of our time,"[50] then the heightened preoccupation relating to the public impact of genetic information derives from its perceived flawlessness. Seen from that angle, its uniqueness if nowhere else lies in its peculiar ability to transform perceptions of the differences among us as "genetic" and therefore immutable,[51]

thus leading to a "medicalization" of racism or sexism[52] that is presented as scientific fact.[53]

Edifying on this last point, the emergence and popularity of "race science" in 19th century European academia resulted in a "belief, backed by the now unassailable authority of science, that racial groups were fixed and immovable, and that nature itself prescribed the domination of superior races over inferior races." [54] As Hudson warns, "We need to be especially wary of the kind of racism linked to the pronouncements of scientists"[55] if only by reason of its unparalleled tenacity. So deeply inculcated are the assertions of the so called "race science" of past centuries, that even subsequent unequivocal evidence of their accuracy could not entirely erase their poisonous vestiges. Scientists enjoy the trust that politicians have lost: Put on a white robe and earn quasi-automatic legitimacy.[56] What is more, members of both the media[57] and the legal profession tend to turn careful equivocal scientific assertions into unequivocal statements.[58] The paradox, as Arthur Caplan observes, is therefore as follows: "Although the predicting capacity of genetic information is flawed at best, people's perceptions of their genes [and those of others] is peculiar" (emphasis added) and indeed fatalistic if not utterly stoic. Dr. Caplan further points out that people tend to be convinced that genetic information is somehow "revealing about their inner blueprint or their inner programming."[59] For her part, Bartha Knoppers labels this "the phenomenon of reductionism," which she refers to as "genes are us, driven by the perception that you are your genes, and you are fatally determined and predisposed by your genetic code."[60]

As previously noted, this is most likely to occur indirectly, even insidiously, as individuals, who happen to belong to or be associated with ethnic or gender minorities susceptible to discrimination, independently seek out the therapeutic benefits of genetic testing. These results can be subsequently compiled used to draw general conclusions in their regard.

While genetic information may ultimately happily serve to disrupt simplistic and misleading notions of ethnicity from whence much of racism derives and potentially lead us to discard *dichotomous* terminology of "race,"[61] the stoicism with which the public tends to embrace "scientific" conclusions[62] arouses concern as to its potential manipulation. Policymakers frequently know too little about science to regulate effectively; the public knows even less.

A related worry is that non-genetic factors will be left unaddressed. As Lee *et al.* caution, "Human cultural identity is relegated to a simplistic biological standar… The elision of economic factors such as poverty, employment, and unequal access to resources… are subsumed within a genetics discourse that reifies notions of physiological difference."[63]

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Importantly, genes only give us *part* of the picture as Yanai Ofran observes, offering the poignant example of Leptin: While mice lost a significant amount of weight, in clinical trials humans surprisingly did not, as scientists had discounted social facts. Ofran points out that people, unlike mice, eat for various social reasons – least amongst them, arguably, is hunger.[64]

As noted above, not only do genetic traits sometimes translate into physical and mental illnesses, they may also manifest themselves as tendencies towards certain behaviors, including violence. To use the example of the reported link between the MAOA gene and abnormally aggressive behavior, such as arson, attempted rape, and exhibitionism. This is far from fiction. A gene closely associated with violent behavior in men has been identified.[65]

In France, children of convicts and other violent offenders have been tested genetically at the embryonic stage, with a recommendation to follow-up with certain children until adulthood for violence propensities purportedly uncovered genetically.[66]

What will happen, as Müller-Hill has asked, if additional "crime genes" related to mutational events are identified and are found to vary in frequency among ethnic groups?[67] As Patrick S. Florencio correctly observes: "whereas non-genetically influenced behavior will be seen as mal-

leable and the product of free will, genetically influenced behavior will be misinterpreted as being unmalleable and beyond the control of the affected individual. This belief has been referred to as "neurogenetic determinism" or "genetic fatalism." [68]

Perhaps of greater concern, as noted, is that our individually centered system, which deems genetic information "personal", is arguably ill-equipped to deal with its public implications, especially where there is discord among particular group members regarding the benefits of testing.

To paraphrase Michel Rosenfeld in a different context, genetic information can "produc[e] individual injuries on account of group affiliation"[69] but also group injuries on account of individual testing. This in turn may, as noted, give rise to a conflict between the best interests of the test subject and his or her group, which the law has yet to address.

Part III

What then can and must we do?

The modest purpose of this endeavor is to draw attention to the social ramifications of genetic discrimination as a first yet necessary step towards reframing the "genetic" legal debate, now narrowly centering chiefly if not solely on personal information primarily in the employment and insurance context.

It is likewise to ensure that any legal responses that are ultimately offered are informed by rights – both individual *and* group – rather than considerations relating exclusively to privacy or health, since the "therapeutic benefits test" as noted, may not always offer the requisite solution in this context. From a human rights perspective, such an approach would recognize multiplicity of interests at stake, beyond privacy, in order to promote more informed policy decisions, most importantly, as noted, human dignity.[70] Finally, in light of science's above-described peculiar propensity to elicit stoic and resilient public acceptance and the simplistic distortion of scientific data in the media, the hope is to similarly invite a renewed focus on the language employed by genetic researchers and those who report on their findings and its potential social implications.

Researchers, as Bhopal cautions, "cannot be responsible for the public's perception of genetics but must be aware of the potential impact of their work on social relations,"[71] particularly when the scientific accuracy of genomic knowledge is – at this early stage – questionable at best.[72] The same holds true for the media and those who premise their arguments on genetic data, *a fortiori*. In her own research, Celeste Condit[73] has emphasized the need to subject the language that genomic researchers employ in their genetic accounts for human variation to greater scrutiny.[74] Even more so do those outside the scientific community, whose parlance tends to be far more unequivocal, need to tread with caution in this vein. It is here perhaps that jurists and indeed the law may have the most valuable informative role to play through increased multidisciplinary collaboration in the area of genomics, for "when we discuss genetics, our words have different meanings." [75]

The discursive constructions of law often dictate the enforcement of prevailing moral and social norms and serve to mold our perception of issues most sensitive to the body politic, such as the exogenous imposition of ethnic or gender/sexual identity. While the intersection between law and culture is nothing new, the manner in which law's linguistic sphere of influence impinges upon budding genomic knowledge pertaining to gender and ethnicity impels further consideration from the optic of human dignity, without the employment and insurance context.

The ultimate goal of human rights scholarship in the area of genetics therefore appears to be developing a broader, more inclusive framework that will assist policy makers and courts in their quest to confront the impact of new technology on the law's development, an undertaking that will occupy both lawmakers and the courts as they struggle with law in the age of the ongoing genomic revolution.

The article (a more detailed version) is forthcoming in the *Journal of Law Medicine and Ethics.*

Notes

[1] S. Simitis, "Reviewing Privacy in an Information Society", *University of Pennsylvania Law Review* 135 (1987): 707 at 709.

[2] E. T. Juengst, "FACE Facts: Why Human Genetics Will Always Provoke Bioethics", *Journal of Law, Medicine & Ethics* 32, no. 267 (2004), at 270-272.

[3] S. Labman, "Genetic Prophecies: The Future of the Canadian Workplace", *Manitoba Law Journal* 30, no. 2 (2004): 227-247 Labman provides the example of a company that screened only African Americans for sickle-cell anemia indicators. The FDA also approved a drug exclusively tailored to African Americans; see S. Saul, "FDA Approves a Heart Drug for African Americans", *New York*

Times, June 24, 2005, at C2. For a thorough discussion and critique of the advent of "race-based medicine" and medical "racial profiling", see S. Hoffman, "Racially-Tailored Medicine Unraveled", *American University Law Review* 55 (2005): 395-452, *available at* <http://www.wcl.american.edu/journal/lawrev/55/hoffman.pdf?rd=1> (last visited February 21, 2007).

[4] See e.g., I. Berlin, "Two Conceptions of Liberty" in Four Essays on Liberty (Oxford University Press, 1969).

[5] CTV.ca News Staff, "Quebec Radio Shrink Sparks Complaints of Racism", (September 29, 2005), *available at* <http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20050928/mailloux_defends_050928/20050928?hub=Canada> (last visited April 17, 2006).

[6] *Ibid*. On his French-language program, broadcast by radio station CKAC, Pierre Mailloux suggested the artificial selection inherent to slavery left black and Native North Americans with an intellectual deficit: "Those blacks who were too intelligent, too tricky, they were slaughtered", Mailloux said. "It's the consequence of an artificial selection. They can run faster, they're stronger, but their IQs are consistently lower."

[7] G. Cochran, J. Hardy, and H. Harpending, "Natural History of Ashkenazi Intelligence", *Journal of Biosocial Science* 35, no. 5 (2006): 659-693, available at <http://homepage.mac.com/harpend/.Public/AshkenaziIQ.jbiosocsci.pdf> (last visited February 21, 2007).

[8] See J. A. Barondess, "Care of the Medical Ethos, with Some Comments on Research: Reflections after the Holocaust", *Perspectives in Biology and Medicine* 43, no. 3 (2000): 308-324. As Green *et al.* note, "Historically, genetic information has been used to discriminate against individuals and groups, particularly Jews and other minorities." See H. Markel, "The Stigma of Disease: Implications of Genetic Screening", *American Journal of Medicine* 93, no. 2 (1992): 209-215. Markel observes that stigmatization and ostracism of those who are found to have "undesirable" traits after genetic screening could increase. Comparing genetic screening to quarantine, he reminds us that the healthy separated themselves from the "ill", providing two examples of when genetics were applied to American social policy: the early 20th century eugenics movement and the 1970s screening programs for sickle cell anemia.

[9] It should be noted that not surprisingly perhaps, interest in Jewish genetics has been particularly keen. Thus, for instance, the tradition that Kohanim (Jewish High Priests of the Jerusalem Temple) are descended from Aaron was supported by genetic testing. See Skorecki et al., "Y Chromosomes of Jewish Priests", *Nature* 385, no. 6611 (1997): at 32. Research similarly suggests that a significant percentage of Ashkenazi maternal ancestry is also of Middle Eastern origin. A 2006 study by Behar *et al*., based on haplotype analysis of mitochondrial DNA (mtDNA), suggested that about 40% of the current Ashkenazi population is descended matrilineally from just four women. These four "founder lineages" were "likely from a Hebrew/Levantine mtDNA pool" originating in the Near East in the first and second centuries CE. According to the authors, "The observed global pattern of distribution renders very unlikely the possibility that the four aforementioned founder lineages entered the Ashkenazi mtDNA pool via gene flow from a European host population." See D. M. Behar et al., "The Matrilineal Ancestry of Ashkenazi Jewry: Portrait of a Recent Founder Event", *The American Journal of Human Genetics* 78 (2006): 487-497.

[10] Summers ultimately resigned. See Letter from L. H. Summers, "Harvard University: The Office of the President", (February 21, 2006), *available at* <http://www.president.harvard.edu/speeches/2006/0221_summers.html> (last visited February 21, 2007).

[11] In Summers' January 14 remarks, he proposed that innate genetic differences between the sexes may be one explanation for why fewer women succeed in math and science careers. See National Organization for Women, Press Release, *NOW Calls for Resignation of Harvard University's President,* (January 20, 2005), National Organization for Women Website, *available at* <http://www.now.org/press/01-05/01-20-Harvard.html> (last visited February 21, 2007).

[12] See R. A. Zilinskas and P. J. Balint, eds., *The Human Genome Project and Minority Communities: Ethical, Social and Political Dilemmas*, (Westport, CT: Praeger, 2001).

[13] M. A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997).

[14] A. Epstein, "The Legal Regulation of Genetic Discrimination: Old Responses to New Technology", *Boston University Law Review* 74 (1994): See R. M. Green and A. M. Thomas, "DNA: Five Distinguishing Features for Policy Analysis", *Harvard Journal of Law and Technology* 11, no. 3 (1998): 571-591. Green and Thomas state: "[T]he influx of genetic science into biomedicine and research raises the question of whether predictive or diagnostic information derived from the molecular analysis of DNA merit distinctive legal consideration or policy treatment." See C. S. Diver and J. Maslow Cohen, "Genophobia: What is Wrong with Genetic Discrimination?" *University of Pennsylvania Law Review* 149 (2001): 1439 See also G. J. Annas, "Genetic Prophecy and Genetic Privacy – Can We Prevent the Dream from Becoming a Nightmare?" American Journal of Public Health 85 (1995): 22(1): 109-34, 1996. [hereinafter cited as Annas, "Genetic Prophecy"]. Annas believes that genetic information is "uniquely private and personal" for three reasons: "It can predict an individual's likely medical future; it divulges personal information about one's parents, siblings, and children; and it has a history of being used to stigmatize and victimize individuals." See also L. O. Gostin and J. G. Hodge Jr., "Genetic Privacy and the Law: An End to Genetic Exceptionalism", *Jurimetrics* 40, no. 1 (1999): 21-58 (hereinafter cited as Gostin and Hodge, "Genetic Privacy").

[15] R. J. Pokorski, "Use of Genetic Information by Private Insurers", in T. F. Murphy and M. A. Lappé, eds., *Justice and the Human Genome Project*, (Berkeley: University of California Press, 1994): at 91; T. E. Morelli, "Genetic Discrimination by Insurers: Legal Protections Needed From Abuse of Biotechnology", *HealthSpan* 9:8 (1992): 811R. Mykitiuk and S. Penney, "Screening for Deficits: The Legal and Ethical Implications of Genetic Screening and Testing to Reduce Health Care Budgets", *Health Law Journal* 3 (1995): 235 ((1995) 3 *Health Law Journal* 235-268.) For a comparative perspective see T. Lemmens, "Insurance and Human Genetics: Approaches to Regulation" in David N. Cooper, ed., *Nature Encyclopedia*

of the Human Genome (New York: Nature Publishing Group, 2003): 495-498. T. Lemmens and P. Bahamin, "Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis" in B. M. Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Montreal: Yvon Blais, 1998): 108-275; T. Lemmens, "Can Insurance Law Accommodate the Uncertainty Associated with Preliminary Genetic Information?" Canada Bar Review 83 (2004): 357-409); B. M. Knoppers et al., "Genetics and Life Insurance in Canada: Points to Consider" supplement to "Physicians, Genetics and Life Insurance", *Canadian Medical Association Journal* 170 (2004): 1421-1423, Canadian Medical Association Website, *available at* <http://www.cmaj.ca/cgi/data/170/9/1421/DC2/1> (last visited February 21, 2007) ; T. Lemmens, "Genetics and Insurance Discrimination: Comparative Legislative, Regulatory and Policy Developments and Canadian Options", Special Edition: Precedent and Innovation: Health Law in the 21st Century, *Health Law Journal*, Special Supplement 41 (2003); T. Lemmens, "Selective Justice, Genetic Discrimination and Insurance: Should We Single Out Genes in Our Laws?" *McGill Law Journal* 45 (2000): 347-412 [hereinafter cited as Lemmens, "Selective Justice"].

[16] P. S. Miller, "Is There a Pink Slip in my Genes? Genetic Discrimination in the Workplace", *Journal of Health Care Law and Policy* 3 (2000): 225-265 P. S. Miller, "Genetic Discrimination in the Workplace", *Journal of Law, Medicine & Ethics* 26, no. 3 (1998): 189-197; P. S. Miller, "Analysing Genetic Discrimination in the Workplace" in S. Krimsky and P. Shorett, eds., *Rights and Liberties in the Biotech Age: Why We Need a Genetic Bill of Rights* (Rowman & Littlefield, 2005): 173-178 Lanham:; L. B. Andrews, M. J. Mehlman, and M. Rothstein, *Genetics: Ethics, Law & Policy* (St. Paul, MN: West Publishing, 2002); Paul Steven Miller, "Commentary: Genetic Discrimination in the Workplace", Genetics in Medicine 3 (2001) 165-168; M. R. Natowicz, J. K. Alper, and J. S. Alper, "Genetic Discrimination and the Law", *American Journal of Human Genetics* 50 (1992): 465-475.

[17] D. Hellman, "What Makes Genetic Discrimination Exceptional?" *American Journal of Law and Medicine* 29 (2003): 77-116; P. S. Miller, "Genetic Discrimination: Does it Exist? What are its Implications?" *Journal of Law and Health* 16 (2001): 39- see generally, T. Lemmens and D. R. Waring, eds., *Law and Ethics in Biomedical Research: Regulation, Conflict of Interest, and Liability* (Toronto: University of Toronto Press, 2006). See also L. O. Gostin and J. G. Hodge Jr., "Personal Privacy and Common Goods: A Framework for Balancing under the National Health Information Privacy Rule", *Minnesota Law Review* 86 (2002): 1439-1479.

[18] *Law v. Canada (Minister of Employment and Immigration)*, 1 S.C.R. 497 at paragraph 16 (1999), Canadian Legal Information Institute Website, *available at* <http://www.canlii.org/ca/cas/scc/1999/1999scc17.html> (last visited February 21, 2007) [hereinafter cited as Law].

[19] See G. Bernstein, "Accommodating Technological Innovation: Identity, Genetic Testing and the Internet", *Vanderbilt Law Review* 57 (2004): 963-1040. Bernstein suggests "a socially oriented approach that focuses on the impact of technological innovation on social structures, institutions, and values and on our ability to mold these social influences by restructuring uses of new technologies: reciprocal interaction between the technological, social, and legal spheres – our normative conceptions of identity; genetic testing and the Internet continuously alter the social structures through which we perceive our identity, thereby causing social transformation."

[20] R. Bhopal, "Is Research into Ethnicity and Health Racist, Unsound, or Important Science?" *British Medical Journal* 314 (1997): 1751-1756.

[21] T. Caulfield and G. Robertson, "Eugenic Policies in Alberta: From the Systematic to the Systemic?" *Alta. Law Review* 35 (1996): 59-79.

[22] G. J. Annas, "Mapping the Human Genome and the Meaning of Monster Mythology", *Emory Law Journal* 39 (1990): 629-664 [hereinafter cited as Annas, "Mapping the Human Genome"].

[23] T. H. Murray, "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from other Medical Information" in M. A. Rothstein, ed., *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (New Haven: Yale University Press, 1997): at 60. See also M. A. Rothstein, "Genetic Privacy and Confidentiality: Why They are So Hard to Protect", *Journal of Law, Medicine & Ethics* 26, no. 3 (1998): 198-204.

[24] L. Gannett, "Racism and Human Genome Diversity Research: The Ethical Limits of 'Population Thinking'", *Philosophy of Science* 68 (2001): S479. Gannett's article raises concerns of racism in the Human Genome Diversity Project by UNESCO, noting that the medical information obtained thereby could be misused by people seeking to propagate racism.

[25] S. Becker, "Constitutional Classifications and the 'Gay Gene'", *Journal of Law and Health* 16 (2001): 27-32.

[26] For a general discussion see B. M. Dickens, N. Pei, and K. M. Taylor, "Legal and Ethical Issues in Genetic Testing and Counselling for Susceptibility to Breast, Ovarian and Colon Cancer", *Canadian Medical Association Journal* 154 (1996): 813818 .

[27] Considered to be a side effect of genes selected for their role in boosting brain function – a thesis set forth in the above-cited research; see Cochran, Hardy, and Harpending, *supra* note 7. See also Labman, *supra* note 4. The article discusses people's reticence to participate in 'genetic' cancer research studies for fear of being stigmatized as having a predisposition towards cancer. See also Green and Thomas, *supra* note 15, at 586-587.

[28] S. G. Stolberg, "Concern Among Jews is Heightened as Scientists Deepen Gene Studies", *New York Times*, April 22, 1998, at A24. See H. T. Greely, *Neuroethics*: *The Neuroscience Revolution, Ethics, and the Law,* paper presented for the Regan Lecture, April 20, 2004, Markkula Center for Applied Ethics Website, *available at* <http://www.scu.edu/ethics/publications/submitted/greely/neuroscience_ethics_law.html>. Somewhere between 50 and 85 percent of women born with a pathogenic mutation in either of those genes will get breast cancer; 20 to 30 percent (well under half) will get ovarian cancer.

[29] L. Soleymani Lehmann et al., "A Population-Based Study of Ashkenazi Jewish Women's Attitudes toward Genetic Discrimination and BRCA 1/2 Testing", *Genetics in Medicine* 4 (2003): at 346, 348 (observing that thirteen

percent of Jewish women surveyed feared that "that BRCA 1/2 testing will lead to increased anti-Semitism"). J. G. Hodge Jr., "Health Information Privacy and Public Health", *Journal of Law, Medicine & Ethics* 31, no. 4 (2003): 663-683 (hereinafter cited as Hodge, "Health Information Privacy").

[30] J. K. Frizzley, "Ethical Issues in Breast Cancer Susceptibility Testing", *Health Law Review* 6, no. 2 (1991): 14-23.

[31] P. S. Florencio, "Genetics, Parenting and Children's Rights in the Twenty-First Century", *McGill Law Journal* 45 (2000): 527-558 ; see generally K.C. Glass, "Research Involving Humans" in J. Downie, T. Caulfield, and C. M. Flood, eds., Canadian Health Law and Policy, 2nd ed. (Toronto: Butterworths Canada, 2002): 459-500 E. J. Emanuel et al., eds., *Ethical and Regulatory Aspects of Clinical Research:* Readings and Commentary (Baltimore, MD: Johns Hopkins University Press, 2003); S. Krimsky, "Human Gene Therapy: Must We Know Where to Stop Before We Begin", *Human Gene Therapy* 1 (1990): 71.

[32] A. Goldworth, "Informed Consent in the Genetic Age", *Cambridge Quarterly of Healthcare Ethics* 8 (1999): 393-400. For example, Goldworth focuses on the importance of autonomy and the need to give informed consent.

[33] See Stolberg, *supra* note 30.

[34] See Annas, "Mapping the Human Genome", *supra* note 23.

[35] Ritchie Witzig, "The Medicalization of Race: Scientific Legitimization of a Flawed Social Construct", *Annals of Internal Medicine* 125 (1996): 675-XXX.

[36] Regarding impulsive violence, see the groundbreaking research conducted by A. Meyer-Lindenberg *et al*., "Neural Mechanisms of Genetic Risk for Impulsivity and Violence in Humans", *Proceedings of the National Academy of Sciences of the United States of America* 103 (2006): 6269-6274 [hereinafter cited as Meyer-Lindenberg, "Neural Mechanisms"]. "Our data identify differences in limbic circuitry for emotion regulation and cognitive control that may be involved in the association of *MAOA* with impulsive aggression, suggest neural systems-level effects of X-inactivation in human brain, and point toward potential targets for a biological approach toward violence." See also Andreas Meyer-Lindenberg *et al*., "Neural Correlates of Genetically Abnormal Social Cognition in Williams Syndrome", *Nature Neuroscience* 8 (2005): 991-993, Unit for Systems Neuroscience in Psychiatry Website, *available at* <http://snp.nimh.nih.gov/Papers/Nature%20Neuroscience%202005c.pdf> (last visited February 21, 2007).

[37] See N. Hudson, "The Race Debate", *The Globe and Mail*, June 20, 2005, at A18. "The term 'race,' understood as a label for large groups characterized by traits such as skin colour, did not emerge until the late 18th century when it was coined by scientists Georges-Louis Leclerc Buffon and Johann Friedrich Blumenbach."

[38] S. Soo-Jin Lee, J. Mountain, and B. A. Koenig, "The Meanings of 'Race' in the New Genomics: Implications for Health and Disparities Research", 1 *Yale Journal of Health Policy, Law, and Ethics* 1 (2001): at 33-75, at 60.

[39] See J. Burley, ed., *The Genetic Revolution and Human Rights: The Oxford Amnesty Lectures* 1998 (Oxford: Oxford University Press, 1999). See also R. E. Howard-Hassmann, "Canadians Discuss Freedom of Speech: Individual Rights Versus Group Protection", *International Journal on Minority and Group Rights* 7, no. 2 (2000): 109-138. Although the focus of this particular piece is freedom of expression, its discussion of individual versus group rights, with particular respect to vulnerable groups, is relevant.

[40] See also D. L. Wiesenthal and N. I. Wiener, "Privacy and the Human Genome Project", *Ethics and Behavior* 6 (1996): 189-202.

[41] R. S. Schwartz, "Racial Profiling in Medical Research", *New England Journal of Medicine* 44 (2001): 1392-1393; see Annas, *supra* note 15. Annas argues Federal protections are lacking.

[42] B. M. Knoppers, "Human Genetics: Parental, Professional and Political Responsibility", *Health Law Journal* 1 (1993): 13-23.

[43] At the state level only, as addressed *infra*. For a more detailed discussion see S. Hoffman, "Legislation and Genetic Discrimination", *Journal of Law and Health* 16 (2001): 47-51.

[44] See Gostin and Hodge, *supra* note 15.

[45] *Ibid*. See also P. S. Florencio and E. 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", *Osgoode Hall Law Journal* 39 (2001): 77. 116.

[46] T. Lemmens forcefully argues that anti-discrimination legislation is not necessarily required as it is doubtful that genetic information can be demarcated from other health related data for purposes of insurance, for instance: "It is debatable whether genetic information is sufficiently distinct from other medical information as to justify its special treatment by the law, such as through the enactment of specific genetic privacy and anti-discrimination legislation." (See Lemmens, *supra* note 16, at 83).

[47] In Canada, the only legislation that deals directly with genetic information, outside of the DNA warrants and other criminal law stuff in the Code, are the provisions dealing with human cloning in the *Assisted Human Reproduction Act,* R.S.C. 2004 c. 2, s.40.

[48] This is of particular concern in light of what is described as the likely expansion of the private market for genetic testing. For a more detailed discussion see B. Williams-Jones, "Private Genetic Testing in Canada: A Summary", *Health Law Review* 9 (2001): 10, Health Law Institute Website, *available at* <http://www.law.ualberta.ca/centres/hli/pdfs/hlr/v9_3/brynfrm.pdf> (last visited February 21, 2007). In the same vein, see T. A. Caulfield, M. M. Burgess, and B. Williams-Jones, "Providing Genetic Testing through the Private Sector – A View from Canada", *Canadian Journal of Policy Research* 2 (2001): 72-81, Canadian Journal of Policy Research Website, *available at* <http://www.isuma.net/v02n03/caulfield/caulfield_e.shtml> (last visited February 21, 2007). The authors observe: "Genetic testing technologies are rapidly moving from the research laboratory to the market place. Very little scholarship considers the implications of private genetic testing for a public health care system such as Canada's. It is critical to consider how and if these tests should be marketed to, and purchased by, the public. It is also imperative to evaluate the extent to which genetic tests are or should be included in Canada's public health care system, and the

impact of allowing a two-tiered system for genetic testing. A series of threshold tests are presented as ways of clarifying whether a genetic test is morally appropriate, effective and safe, efficient and appropriate for public funding and whether private purchase poses special problems and requires further regulation. These thresholds also identify the research questions around which professional, public and policy debate must be sustained: What is a morally acceptable goal for genetic services? What are the appropriate benefits? What are the risks? When is it acceptable that services are not funded under health care? And how can the harms of private access be managed?"; see also N. A. Holtzman, "The UK's Policy on Genetic Testing Services Supplied Direct to the Public – Two Spheres and Two Tiers", *Community Genetics* 1 (1998): at 48-52, at 49; and T. A. Caulfield and B. Williams-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal and Policy Issues* (New York: Kluwer Academic/Plenum Publishers, 1999): at 181.

[49] The Honorable Robert K. Rae, "The Courts and Group Rights in Canada", *Saint Louis University Law Journal* 42 (1997): 539-544. See *Law*, *supra* note 20

[50] Irwin Cotler refers to human rights as the "secular religion of our times" in "Human Rights and the New Anti-Jewishness", *Justice* 38 (2004): at 24-30, at 27.

[51] "The root of genetic discrimination is what George Annas has dubbed "genism", which he defines as "the theory that distinctive human characteristics and abilities are determined by genes."

[52] With respect to women particularly, see F. Miller et al., *eds., The Gender of Genetic Futures: The Canadian Biotechnology Strategy, Women and Health. Proceedings of a National Strategic Workshop Held at York University, February* 11-12, 2000 (Toronto: York University, 2000), National Network on Environments and Women's Health Website, *available at*<http://www.yorku.ca/nnewh/english/pubs/genderofgeneticfuturesfull.pdf > (last visited February 22, 2007).

[53] As was the case of the above-cited Montreal psychiatrist. As Barondess warns, "[w]e face the possibility of a new eugenics that is immensely more powerful because it is based on valid science." See Barondess, *supra* note 9.

[54] See Hudson, *supra* note 39.

[55] *Ibid*.

[56] For a more detailed reflection on the trust accorded scientists from a sociology perspective, see K. M. Leisinger, "Science and Public Trust", lecture presented to the Engelberg Forum, October 2002, Novartis Foundation for Sustainable Development Website, *available at* <http://www.novartisfoundation.com/pdf/leisinger_science_public.pdf> (last visited February 22, 2007).

[57] See J.-P. Rogel, *Genetique et Medias: Histoire d'un Malentendu?*, paper presented to When Science Becomes Culture International Symposium, April 1994, Centre interuniversitaire de recherche sur la science et la technologie Website, *available at* <http://www.cirst.uqam.ca/PCST3/PDF/Communications/ROGEL.PDF> (last visited February 22, 2007). See above article for a discussion on the media's tendency to aggrandize and unequivocate scientists' statements relating to their research in genetics.

[58] T. Duster, "Human Molecular Genetics and the Subject of Race: Contrasting the Rhetoric with the Practices in Law and Medicine", keynote address presented to the West Harlem Environmental Action conference and community dialogue on Human Genetics, Environment, and Communities of Color: Ethical and Social Implications, February 2002. See generally W. M. Sage, "The Lawyerization of Medicine", *Journal of Health Policy* 26 (2001): 1179-1195.

[59] According to Dr. Caplan, people tend to believe that their genes are somehow "revealing about their inner blueprint or their inner programming." See A. Caplan, "Are We Ready for Mass Genetic Testing: Ethical and Social Hurdles?", lecture presented to the Annual Meeting of Women in Biotechnology, October 2002, at 5, New York University School of Medicine: Research Computing Resource Website, *available at* <http://mcrcr0.med.nyu.edu/training/caplan.pdf > (last visited February 22, 2007).

[60] B. M. Knoppers, "Overview of Law and Policy Challenges", Special Issue, *Louisiana Law Review* 66 (2005) 21-31.

[61] See Gannett, *supra* note 25. See also Duster, *supra* note 85.

[62] J. C. Hoeffel, "The Dark Side of DNA Profiling: Unreliable Scientific Evidence Meets the Criminal Defendant", *Stanford Law Review* 42 (1990): 465-492.

[63] A related issue is the growing enthusiasm for drugs that are tailored for use with specific racial or ethnic groups. This concept is based on the problematic assumption that race can be used as a visible marker for a certain genotype, an assumption that is bound to be false in some cases and could lead to stereotyping with serious health implications. Studies have shown that existing drugs for treatment of cardiac patients were not effective in African Americans. See e.g., D. V. Exner et al., "Lesser Response to Angiotensin-Converting-Enzyme Inhibitor Therapy in Black as Compared with White Patients with Left Ventricular Dysfunction", *New England Journal of Medicine* 344 (2001): 1351-1357. (For a good review, see R. S. Cooper, J. S. Kaufman, and R. Ward, "Race and Genomics", *New England Journal of Medicine* 348 (2003): 1166-1170. See J. Kahn, "How a Drug Becomes 'Ethnic': Law, Commerce, and the Production of Racial Categories in Medicine", *Yale Journal of Health Policy Law and Ethics* 4:1 (2004): 1-46), for a very interesting discussion of how the FDA subsequently approved a "new" drug exclusively for use in African Americans, essentially allowing the drug company to extend patent protection on an existing drug. If these kinds of drugs continue to be developed, it could lead to a surge in the number of individuals seeking testing, which in turn could further enhance the idea in the general population that cardiovascular disease in African Americans is entirely genetic, when in fact it is just as likely to be the result of poor diet and other social determinants of health factors related to systematic oppression and poverty.

[64] Y. Ofran, "What Can We (and What Can't We) Infer from Biological Information (2005)", University of Haifa Faculty of Law Website, *available at* <http://law.haifa.ac.il/events/event_sites/gen/Presentations/yanay.pdf> (last visited February 22, 2007).

[65] See Meyer-Lindenberg, *supra* note 38: "Our data identify differences in limbic circuitry for emotion regulation and

cognitive control that may be involved in the association of *MAOA* with impulsive aggression, suggest neural systems-level effects of X-inactivation in human brain, and point toward potential targets for a biological approach toward violence."

[66] S. Simitis, *The Legal Limits of Genetic Research and Results*, report presented to the XIIth Congress of the International Academy of Comparative Law, July 2006.

[67] B. Müller-Hill, "Truth, Justice, and Genetics", *Perspectives in Biology and Medicine* 43 (2000): 577-583.

[68] See Annas, *supra* note 15; see also E. Toback and H. M. Proshanky, eds., *Genetic Destiny: Race as a Scientific and Social Controversy* (New York: AMS Press, 1976).

[69] M. Rosenfeld, "Can Human Rights Bridge the Gap between Universalism and Cultural Relativism? A Pluralist Assessment Based on the Rights of Minorities", *Columbia Human Rights Law Review* 30 (1999): 249.

[70] J. Harris and J. Sulston, "Genetic Equity", *Nature Reviews Genetics* 5 (2004): 796-800, at 796.

[71] See Bhopal, *supra* note 21.

[72] While genetic knowledge is, as Professors Harris and Sulston astutely observe, at the zenith of its "prestige", its scientific accuracy, paradoxically, is not. These leading researchers, particularly Nobel laureate Sir Sulston, urge the development of a moral and legal "compass" to inject equity into the furtherance of genomic knowledge. (See Harris and Sulston, *supra* note 95).

[73] A professor of speech communication at the University of Georgia who specializes in biomedical issues.

[74] Condit argues: "Usually scientists are very careful in developing their technical vocabulary. But it's hard to describe the geographic dispersion of people properly – and they have these easy [racial] terms in their heads." Quoting Carolyn Abraham: "Despite the long and ugly social history of race, there is no clear-cut definition for the term. Is a person's race defined by skin colour, that most visible of markers? By language, country of birth, the food they eat or the religion they practice? Not even scientists can agree…[i]f you have a [genetic] sample from Nigeria, can you really say that it represents Africans? Is that the same as African Americans? [In some studies], Jews are white, sometimes they're not. Sometimes they're compared to Caucasians." C. Abraham, "Race", *The Globe and Mail*, June 18, 2005, at F1. See also C. Condit *et al.*, "Psycho-social, Clinical and Scientific Barriers to Race-Based Genetic Medicine?" (2004), University of Georgia Biomedical and Health Sciences Institute Website, *available at* <http://www.biomed.uga.edu/RaceBasedMedicine2.pdf> (last visited February 22, 2007).

[75] E. M. Petty and S. R. Kardia *et al.*, "Genetic Variation, Race and Culture", *Journal of Law, Medicine & Ethics* 29 (2001): 39.