INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

ProQuest Information and Learning 300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA 800-521-0600

UMI®

Genetic States: Collective Identity and Genetic Nationalism in Iceland and Québec

Stephanie Lloyd Department of Anthropology McGill University, Montreal Submitted September 2001

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements of the degree of MA.

© Stephanie Jean Lloyd 2001



National Library of Canada

Acquisitions and Bibliographic Services

395 Wellington Street Ottawe ON K1A 0N4 Canade Bibliothèque nationale du Canada

Acquisitions et services bibliographiques

395, rue Wellington Otawa ON K1A 0N4 Canada

Your No. Voere rélérence

Our lite Name rélérance

The author has granted a nonexclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission. L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-75240-2



Abstract

Population genetics studies, coupling genealogical and genetic information, are being launched in many places around the world. Examples include commercial projects, scientific inquiries into the determinants of disease, efforts to better understand healthcare needs, and attempts to trace the histories of groups. Two such studies have been launched in Iceland and Québec. One of the motives for the creation of and participation in these projects is a personal interest in learning about one's genetic lineage and a collective pride in a putative national genetic identity. In this thesis I will be examining how new genetic information has been drawn into claims of national identity and how genetic technologies have been used to create imagined genetically homogenous communities.

Abstract (French)

La recherche des populations génétique, accouplement généalogique et l'information génétique, sont lancées dans beaucoup d'endroits autour du monde. Les exemples incluent des projets commerciaux, des enquêtes scientifiques dans les causes déterminantes de la maladie, des efforts de comprendre mieux les besoins de healthcare, et des tentatives de tracer les histoires des groupes. Deux telles études ont été lancées en Iceland et Québec. Un des motifs pour la création de et la participation à ces projets est un intérêt personnel en se renseignant sur la lignée génétique d'one.s et une fierté collective dans une identité génétique nationale putative. Dans cette thèse j'examinerai à quel point la nouvelle information génétique a été tirée dans des réclamations d'identité

nationale et comment des technologies génétiques ont été employées pour créer les communautés génétiquement homogenous imaginées.

Acknowledgements

I would like to thank my supervisor, Allan Young, for his advice and assistance throughout my MA and during my thesis preparation. My thanks go to Margaret Lock for her comments on an earlier draft of my thesis and for the conversations that helped me to form the concepts presented in my thesis. I would also like to express thanks for her understanding and the 'flexibility' she offered me in my work schedule this summer. I thank Laurence Kirmayer for his intellectual contributions to my work.

I thank Rose Marie Stano, Lisa Stevenson, Adele Ciani Tarantino, and Diane Mann for their understanding and organizational help along the way.

I thank my fellow students in the department of Social Studies of Medicine for their support and encouragement. My hearty thanks go to Ari Gandsman who kept me going throughout many set backs along the way. I thank Karine Vanthuyne and Janalyn Prest for their words of encouragement. I would also like to thank Caroline Tait, Dominique Behague, Vinh-Kim Nguyen, Jennifer Cuffe, Yasir Khan, Janet Childerhose, Mary Ellen MacDonald, Melanie Rock, and Martha Poon for their thoughtfulness and their suggestions.

I thank my friends and family for their unconditional support.

Table of Contents

Part I: Nationalism and biological national identities	5
Section i: The origins of the concept of national identity Section ii: Biological models of the 19 th century Section iii: Social theories drawn from 19 th century biological models,	5 9
biological nationalism, and racism	12
Section iv: The crisis of national identity post-1950	26
Section v: The contemporary role of genes in claiming and creating a national identity	30
Section vi: The role of anthropologists in racial research and anthropological	50
reactions to this involvement	35
Part II: Population genetics and the Human Genome Project	39
Section i: The concept of population genetics until the time of the Human	
Genome Project	39
Section ii: The promise of the Human Genome Project	42
Section iii: Medical promise of the Human Genome Project	45
Section iv: Commercial benefits of the Human Genome Project	50
Part III: Comparison of population genetics projects in Iceland and Québec	54
Section i: Population genetics in Iceland	56
Section ii: Population genetics in Québec	61
Section iii: Scientific goals and challenges to the scientific basis of population	
genetics research	66
Section iv: Concerns about the management and operation of population	
genetics projects	70
Section v: Reasons for participation in population genetics research and the creation of genetic nationalism	71
Part IV: Conclusions	79
References	82

PART I: Nationalism and biological national identities

Section i: The origins of the concept of national identity

Nationalism and national identity are commonly acknowledged concepts around much of the world today. Their existence is often taken for granted, as though they have continuously existed throughout different times and spaces. However these concepts, as a means to identify groups emerged relatively recently. Benedict Anderson and Anthony Smith, among others, have emphasized the historical embeddedness of nationalism. In Imagined Communities, Anderson describes nationality, nation-ness and nationalism as "cultural artefacts of a particular kind," (Anderson 1991: 4)¹ These cultural artefacts were brought together at the end of the 18th century by a "complex 'crossing' of discrete historical forces" in Western Europe. (Anderson 1991: 4) One 'artefact' was the fall of religion during this period, which he claims led to the loss of belief in paradise and salvation. Uncertainty about the origins of humans was also created by the fall of religion. Nationalism filled these gaps and created a sense of continuity out of fatality and meaning out of contingency. (Anderson 1991: 11) Another historical force weakened at this time was natural organization of societies in a hierarchical manner under high centres, such as monarchs. Anderson describes it as "no surprise" that a new means of linking fraternity, power and time was sought out. (Anderson 1991: 36) Anderson's thesis attributes the creation of nationalism to these cultural and temporal particularities of the 18th century.

Anthony Smith also emphasizes the invented nature of the nation and describes nationalism as a historical movement "par excellence." Like Anderson, Smith asserts

¹ For this essay, I am using the revised edition of Anderson's book, originally published in 1983.

that nationalism only emerged in a particular epoch of European history; it is a sentiment or movement that only manifests itself in specific historical situations. (Smith 1992: 58) However, Smith describes nationalism as an instrumental movement, Anderson does not. For example, according to Smith, in pursuit of politically motivated goals, a group may create myths of their past to invent a national identity. This national identity could then be incorporated into a political movement with the goal of creating a nation.

The origin of the concept of national identity is often traced to Johann Gottfried Herder (1744-1803). Herder's writings on the nation reflected the Enlightenment ideals of his day, emphasizing the subjective over the objective, while rejecting universal, discoverable, and timeless laws. (Berlin 1976: 145) His belief that "every activity, situation, historical period, or civilization possessed a unique character," is reflected in his statement, "We live in a world we ourselves create." (quoted in Berlin 1976: 143) Herder introduced new concepts through his writings, notably populism and pluralism. Populism is described as "the belief in the value of belonging to a group or culture." For Herder, this was not a political concept; in fact it opposed the concept of political nationalism by targeting 'grass roots' groups rather than 'etatists'.² (Berlin 1976: 153, 183) The concept of pluralism introduces "the belief not merely in the multiplicity, but in the incommensurability, of the values of different cultures and societies and, in addition, in the incompatibility of equally valid ideals." Pluralism was revolutionary in its 'radical denial' of a single "Great Society" in which a "broad identity or similarity of purpose in all known forms of human activity, universal and timeless goals of men" was recognized.

² Berlin points out that despite Herder's intentions, historically populism has "provided the soil in which blind xenophobia and irrationalism grew to dangerous heights." (Berlin 1976: 184)

Herder's concept of pluralism introduced the idea that different civilizations grow in different ways, pursue different goals, embody different ways of living and are dominated by different attitudes towards life. (Berlin 1976: 153, 209, 210) The concept of pluralism contributed directly to the concept of distinct national identities. Together, populism and pluralism are central to Herder's concept of national identity.

Although Herder coined the word Nationalismus, his version of national identity was particular in its orientation, it did not have the competitive aspect often associated with the nationalism today. (Berlin 1976: 181) Herder's form of national identity was based on a collection of individual attachments to one's "family, language, one's own city, one's own country," and the country's traditions. (Berlin 1976:157) Attachment or pride in these aspects of identity, was not based on a ranking of other nations versus one's own. Rather, it was based on a celebration³ of the unique spirit of Germany's national character. Herder viewed nations as comparable but not commensurable. (Berlin 1976: 149, 181) According to Berlin, Herder's view of the nation and society, "is closer to the anarchism of Thoreau or Proudhon or Kropotkin, and to the conception of a culture (Bildung) of which such liberals as Goethe and Humboldt were proponents, than to the ideals of Fichte or Hegel or political socialists." (Berlin 1976: 181) Herder detested the state and the power and domination of government and bureaucracy. (Berlin 1976: 157, 181, 183) His aim was not political self-determination, but cultural self-determination. Despite his cultural formulation of *Naltionalismus*, it is clear that this conception of national identity could have been an early stage of an aggressive and state-based form of

³ Celebration, or celebrate, is the word Berlin used in reference to Herder's writings on Germany. "He celebrates German beginnings, because they are part of, and illuminate, his own civilization..." (Berlin 1976: 181)



nationalism even if Herder did not aspire to these later stages. (Berlin 1976: 182, 184) For Herder, nationality was a cultural attribute. Society and culture were organic entities and language, tradition, cultural heritage were the most 'vivid expressions' of the *Seele des Volkes*; they were central to Herder's concept of a nation. (Berlin 1976: 149, 183)

But was Herder's *Naltionalismus* a form of nationalism, that is a willingness to defend his cultural heritage and celebrate his civilization? Yes, according to Berlin, in the "obvious sense" of a pride in one's group. Though his formulation of *Nationalismus* was limited to culture and anti-political in its orientation, Herder's work marks the origin of contemporary concepts of 'nationalism' and 'national identity'.

There are many forms of nationalism, two of these are particularly interesting for this paper. John Hutchinson's concept of 'cultural nationalism' resembles Herder's *Nationalismus*. (chapter six in Smith 1992) Similar to Herder's form of nationalism, Hutchinson describes cultural nationalism as absent of political goals. It originates outside of the state among historical scholars and artists. Resembling Herder's nationalism, cultural nationalism is based upon 'love' of a group's common heritage and a celebration of the distinctiveness⁴ of a society. Herder and Hutchinson's concepts differ in that Hutchinson's concept of cultural nationalism is based upon ranking one's nation above others, an idea that Herder condemned. Hutchinson traces cultural nationalism back to the late 18th century. He suggests that it arises in response to a social crisis within a group, often during the integration of new, or 'modern' ideas, people or

⁴ This celebration often takes place by drawing upon traditional practices and 'myths' to regenerate the present culture.

institutions. (Hutchinson 1992: 106, 110) Hutchinson claims that in these times of crisis, groups draw upon their past, as it is described by historians and artists, to promote regeneration of their society according to the tenets of "indigenous cultures and institutions." The goal is a new 'golden age' of their society. (Hutchinson 1992:107) The process of promoting cultural nationalism in this way, according to Hutchinson, involves "myth making." Intellectuals:

combine a romantic search for meaning with a scientific zeal to establish on authoritative foundations the nation's honour as a distinctive people with a high civilization and the laws of its development. These histories typically present a set of mythic patterns: a migration story, the time of settlement, a golden age of cultural splendour, the fall into a dark age, a period of regeneration, perhaps beginning in the present. (Hutchinson 1992: 103)

Though not political in its original phases, Hutchinson suggests that cultural nationalism regularly gives way to political nationalism. (Hutchinson 1992: 111) Political nationalism, in contrast to cultural nationalism, aims to create an autonomous state based on common citizenship and egality (at least in its ideal form). Political nationalism – i.e. the pursuit of an autonomous state – resembles Ernest Gellner's concept of nationalism. According to Gellner, nationalism is "a theory of political legitimacy, which requires that ethnic boundaries should not cut across political ones, and, in particular, that ethnic boundaries within a given state... should not separate the power holders from the rest." (Gellner 1983: 1) The introduction of ethnicity into nationalism raises the issue of the role of biology in the nation. Different from national sentiments based on culture, language and tradition, biological or ethnic nationalism represents another powerful force in the creation and attribution of membership and identity.

Section ii: Biological models of the 19th century

Hereditary transmission applies to psychical peculiarities as well as to physical peculiarities. While the modified bodily structure produced by new habits is bequeathed to future generations... It needs only to contrast *national characters* to see that mental peculiarities caused by habit become hereditary. We know that there are warlike, peaceful, nomadic, maritime, hunting, commercial, races – races that are independent or slavish, active or slothful; we know that many of these, if not all, have a common origin; and hence it is inferable that these varieties of disposition, which have evident relations to modes of life, have been gradually produced in the course of generations. (Herbert Spencer quoted in Stocking 1968: 240, emphasis added)

Beginning in the 19th century, studies of the natural histories of plants, animals and humans led scholars and the educated masses to consider their species in a new light. The differences between groups that had previously been explained by cultural traditions were increasingly attributed to differences of biology and 'race.' In 1809, J.B. Lamarck published *Philosophie Zoologique*, which Ernst Haeckel describes as "the first scientific outline of a real history of the evolution of Species." Haeckel also points out that the effect of this "remarkable and important book" was none. Lamarck's work was not understood. In *Philosophie Zoologique*, Lamarck outlined how differences emerged between distinct species and 'races.' He attributed present particularities to "former changes of occupation, and... acquired habits." (Haeckel 1898: 70, 79, 83) His theory of transmutation, i.e. acquired change over generations as a result of choice and habit, influenced his contemporaries' ideas about ontogeny. However, his work failed to have a significant impact on phylogenetic understandings of humans.

It was only 50 years later, with the publication of Darwin's Origin of the Species, that the significant developments in the biological sciences during the early 19th century were recognized. Through their inclusion in Darwin's theory of evolution, these developments became more widely understood and reached a broader audience, influencing social and scientific thought. The most revolutionary aspect of Darwin's theory relates to his

description of the mechanical nature of the modification of animals and plants throughout the evolutionary process. That is to say, he attributed evolution to *non-purposive* causes. Darwin also succeeded in moving beyond an ontogenetic study of species and was able to construct a phylogenetic account of adaptation. In 1859⁵, Darwin did not apply his theories of adaptation and heredity to humans, limiting himself to a discussion of plants and animals (humans were not included in this latter group). However, others seized his concepts and took the next step. In 1863, both Thomas Henry Huxley and Karl Vogt⁶ published papers on the origins of man. Darwin published his account of the evolution of humans in 1871, though this work was largely focused on the influence of sexual selection in reproduction on the evolution of humans. He believed that more offspring would be born to people who had the most desirable traits to the opposite sex. (Haeckel 1898: 100-103) Although Darwin discussed the mechanical nature⁷ of evolution, the specific means of hereditary transmission was not identified in his research. An understanding of hereditary transmission of traits was not reached for more than four decades after the publication of *Origin of the Species*.

The 'missing link' in Darwin's theory was discovered, or rather, rediscovered, in 1900. Written in 1865, Gregor Mendel's paper on the 'particulates of heredity' described the process of hereditary transmission in terms of 'unit characters.' Mendel claimed that these unit characters were responsible for the discontinuously alternating passage of

⁷ Haekel uses the term 'mechanical' to describe the evolutionary process found in Darwin's theory. Haekel contrasts this mechanical theory of evolution to what he describes as 'purposive' accounts of evolution. (Haekel 1898: 17)



⁵ 1859 was the year in which Origin of the Species was published.

⁶ Vogt, though he applied Darwin's theory of evolution to humans, traced their origins back to apes, refusing to examine any evolutionary developments prior to apes (Haekel traced an evolutionary path from humans back to amoebas). (Haekel 1898: xxix)

characteristics from parents to the next generations. That is to say, if a parental trait were dominant, it would be expressed in the next generation. If the trait were recessive, it would not appear in the next generation. (Chase 1977: 189; Stocking 1968: 174) This view challenged the 'blending theory,' a popular concept at the turn of the century. According to the blending theory, children's heredity was a combination of the hereditary traits of parents and the average of the total hereditary traits of their ancestors. The practice associated with this theory was called biometry⁸, and specialists of biometric techniques claimed the ability to calculate the rate at which traits would be transmitted between generations. Although these two views seemed incompatible one hundred years ago, the former involving discontinuous and the latter continuous transmission of traits, together, they would form the basis of modern genetics. At the turn of the century, the immediate social importance of Mendelian genetics was its influence on interpretations of 'racial' differences. Certain characteristics were presumed to be intrinsic to each race and these differences could not be modified by environmental conditions (culture, living conditions, education, health care). For those eager to prove biological differences between the 'races,' Mendel's theory supported the importance of 'nature' over 'nurture.' (Proctor 1988: 145 - chapter 5 in Stocking 1988)

Section iii: Social theories drawn from 19th century biological models, biological nationalism, and racism

Lamarckian, Darwinian, and Mendelian theories introduced the concepts of 'race' and 'species' into biological discourses on human difference. The theories were used in both

⁸ Sir Francis Galton was a leading biometrist in the late 19th and early 20th centuries.

scientific and social commentaries. Examples of the latter include Social Darwinism and theories of human 'racial' evolution. By the mid-19th century, rather than describing groups as culturally superior to others, differences were cast in terms of scientific superiority of particular 'races.' Races were organized in a hierarchical manner, ranked according to the traits ascribed to their group, their geographical origin, and level of cultural development, which was seen as the outcome and perpetuator of this racial superiority. A new relationship was constructed between culture and human evolution.⁹ George Stocking notes "the assumption of white superiority was certainly not original with Victorian evolutionists; yet the interrelation of the theories of cultural and organic evolution, with their implicit hierarchy of race, gave it a new rationale." (Stocking 1968: 122) Although a belief in the existence of multiple human 'races' was common, a consensus did not exist in terms of the number of 'races.' However, some consistencies appeared among their groupings and in the ranking of some categories.

'Negroes,' Tasmanians and Australians usually fell at the bottom of the 'racial' hierarchy. These 'savages' were believed to represent an early version of humans who were fundamentally different from 'civilized' men¹⁰, differing in their basic human nature, according to Spencer. (Stocking 1968: 117) Their mental capacity, whose development Spencer tied closely to environmental factors, was thought to reach only the level of sensation, rarely rising above this level and "the simple representative feelings associated

¹⁰ I refer to men at this point because women were sometimes portrayed as sharing characteristics with the lower 'races.'



⁹ The relationship that Spencer saw between society and mental evolution is an example of his Lamarkian theoretical foundations. He believed that the "inherent savage mentality produced a certain type of social life; but savage social life... also produced the hereditary savage mentality." Spencer claimed that the "primitive man' could not evolve higher mental capacities in the absence of a "fit environment," but "his progress was retarded by the absence of capacities which only progress could bring." (Spencer quoted in Stocking 1968: 118)

with them (the sensations)." (Spencer quoted in Stocking 1968: 117) E.B. Tylor believed that the brains of Africans and Europeans were not only functionally different, but also structurally different. Thus, biology separated these two groups, the Africans being the ancestors of the "progressive" Europeans. (Stocking 1968: 115-6) In the 19th century 'racial' hierarchy, Asians were generally considered to be one step above the 'savages' toward civilization. Though it was believed that Asians were less 'aggressive' and 'lazy' than Africans, they were still a large step below Europeans.

More inconsistencies in the division and ranking of 'races' appear when the 'white race' is considered. White skin was consistently associated with civilization. (Stocking 1968: 131) But even among white-skinned human there existed a distinct hierarchy. For instance, Tylor believed that the peasants in his own society shared a less civilized brain structure with Africans. It is uncertain, however, to what degree different brain structures were seen to shape cultures or be shaped by them, according to Tylor's theory. (Stocking 1968: 116) It was generally believed that the upper class were of better 'stock' than the lower class.

There were also strict divisions between the 'white races' in Germany. Léon Poliakov suggests that at the beginning of the 19th century, social and economic changes threw previously existing means of dividing groups, such as Germans and Jews, into confusion. Older juxtapositions of groups according to religions distinctions also became blurred in a secularized society. (Poliakov 1975: 286-91) In the wake of these internal confusions,

several new and competing views of man's history appeared. Among these was a new "Aryan myth" of the origin of the Aryan 'race.'

Poliakov suggests that at this time, everything indicated, "Europe was looking for new ancestors." (Poliakov 1975: 314) Histories and hierarchies of 'races' replaced older means of distinguishing between different groups of people. However, theorists were still bound by certain traditional ideas and so, in organizing and dividing the 'races' into categories, many scholars looked back to the Bible. The division fell into three races, echoing the myth of Noah's three sons. Africans were labelled the "Hamites," Jews were labelled the "Semites," and white people were given the label "Japhetites." However, Germans protested this name and instead chose "Aryan" as the label of their 'race,' being derived from the term 'honour.' (Poliakov 1975: 316-8; Stocking 1988: 4-5)¹¹ These labels differentiated between white and non-white people, but also supported a distinction between the white 'races.' The German Aryans were the most pure of these people, followed by the Danes and Anglo-Saxons.¹² The Jews were placed far below the Aryans and Anglo-Saxons. New race-based prejudices replacing the old religious divisions previously used to compare and rank the groups. (Poliakov 1975: 291)

The distinctions between the white 'races' were also tied closely to their environment. For instance, the Celts, who had 'lost' their blue eyes and blond hair (presumed to be the

¹¹ The distinction of these three 'races' can be traced back to the 16th century, although at the earlier time the groups were considered different 'tribes' or 'nations,' differentiated by their languages. (Stocking 1988: 4 – incidentally, in this case Stocking references Poliakov 1971) What is new about these racial distinctions in the 19th century is that they reference biological 'racial' differences. The addition of an Aryan race is also new.

¹² Of course this classification was subjective. The British and the French would likely have changed the hierarchy created by the other.

result of an environmental adaptation), were considered less 'pure; than the Anglo-Saxons. (Blanckaert 1988: 31-2) This emphasis on the environment is another example of the Lamarckian basis of the 19th century hierarchies of the 'races.' Tylor's statements about the lower mental capacities of the peasants reflect the Lamarckian beliefs of these theorists (here, I include Spencer as well). Because of the Lamarckian basis of these theories, there was a certain degree of flexibility in the 'racial' hierarchies. But this flexibility was limited to the 'white races.' In the proper (that is, culturally developed according to the values of the 19th century theorists) environment, individuals and groups had the potential to better their traits and improve their 'race.'

Different groups of Europeans were ranked based on the purity of their 'race.' The concept of purity raises the issue of blood. 'Blood' was crucial to the 19th century idea of biological hierarchy. However, the concept of blood as a means of distinguishing groups was not new in the 19th century. Blood had been used as a non-literal means of describing a line of people who descend from common ancestors (a line of people could be traced back to a particular group or 'tribe,' or to a specific ancestor as in the biblical example of Shem, Ham and Japheth). Genealogical studies were used since the 16th century as a means for people to trace their lines, or, to establish the purity of their 'blood' in relation to a their founder(s). (Stocking 1988: 4-6; Weingart 1999: 410) In the 19th century, blood was still used in this non-literal or metaphorical way by scholars in order to rank the 'races.' That is, blood was not used in laboratory tests to biologically determine differences between groups. Blood was a symbol of different people – a means to discuss the 'purity' of a 'race.'(Gilman 1991: 101) However, in the 19th

century, this concept of blood was also infused with biological meaning – different physical characteristics were associated with 'pure' as opposed to 'degenerate'¹³ races. Physical weakness and disease were associated with the 'degenerate races,' though degeneration was also tied to social conditions. For instance, socially disvalued habits and trends, such as increased prostitution and alcoholism in Germany were used as proof of the influence of substandard 'blood.' (Proctor 1988: 143) Drawing upon the biological 'proof' of blood-based differences, social theorists such as Joseph Arthur de Gobineau used the concept of 'blood' to 'evidence' to support his racist claims. From these examples it becomes clear that the concept of blood was used at multiple levels of explanation in 19th (and early 20th) century discussions of 'race.'

The concept of evolution, and later, heredity was used to in addition to 'blood' to justify the hierarchy of 'races.' Social evolution, as explained above, was perceived to go handin-hand with biological evolution. The superior and 'pure' 'races' were believed to have evolved into their current stage of civilization. This more advanced evolutionary stage of the 'white race,' and especially the Aryans¹⁴, was used to place these groups at the top of the 'race' hierarchy. The concept of heredity was based on Gregor Mendel's theory of inheritance (the earliest form of genetic studies), and, like the concept of blood, heredity was used to compare and rank 'races.' But instead of reflecting on the purity of a lineage or the genealogy of a group, heredity was used to compare the different 'traits' of groups. Traits were understood to be specific characteristics that would be passed from one generation to the next, such as colour of eyes, hair, and physical features such as a

¹³ A discussion of degeneration follows in this section.

¹⁴ The Aryans were also referred to as the Nordics or Teutons.

particular shape of nose or foot, or susceptibility to alcoholism. Particular traits, like blond hair and blue eyes, were given greater value than others, while traits such as flat feet were disvalued because they were associated with a 'lower race.' (Gilman 1991: 39) Much like the concept of 'blood,' the concept of genetic heredity was used to reinforce, or create, a *social* hierarchy of the 'races.' Scientific studies were also performed in an effort to understand the transmission of traits, but the outcomes and conclusions drawn from these studies were often heavily influenced by the bias of the scientist.¹⁵

Joseph Arthur de Gobineau, Francis Galton, Herbert Spencer, and Werner Sombart were largely responsible for the transfer of 19th century biological theories into social movements. However, the use of these racial concepts was not limited to promoting their own group. In the case of the Jews, certain of their traits were considered superior to those of the Germans. For instance, Nietzsche, though German, attributed to the 'Semitic race' almost "superhuman powers, and he traced this power to their heredity, to their 'blood.'" (Poliakov 1985: 8-10) It should be pointed out that Nietzsche used the term 'race' in a way that Poliakov believes must have been paradoxical. He did not use race in the same way as typical racists of the 19th century. (Poliakov 1985: 10) Another German, Wilhelm Marr, in his book *The Victory of Judaism over Germanism*, attributed the Jewish dominance in Germany (1871-2) to their "racial qualities." However, Marr was not attributing superior qualities to the Jews in a complimentary fashion, as had Nietzsche.

¹⁵ For example, Eugen Fischer studied and 'proved' that physical racial traits segregate in a Medelian fashion based on his 1908 study of the intermarriages between the Dutch and Hottentots. Fischer believed it was "very probable" that spiritual or behavioural traits were heritable in the same fashion. His study was premised on his concerns about the degeneration of the "magnificent German people" as a result of intermarriage with Jews. His findings lent weight to his belief that the two 'races' should be segregated. (Proctor 1988: 144-6)



He was not accepting their dominance, he was identifying a problem; in 1879 he founded an anti-Semitic league. (Poliakov 1985: 17-18) By praising the intelligence of the Jews, Marr, among other German scholars, was identifying a pathology. That is, the Jews were a social pathology in Germany, victimizing German Christians.

While the Jews were cast as a pathology for certain of their 'superior qualities,' including economic prowess and intelligence, (Gilman 1991: 129) anti-Semites identified other types of 'Jewish pathologies.' These pathologies, unlike the attribution of greater intelligence, were negative qualities. The Jews' racial inferiority, as determined by anti-Semites, was related to particular diseases and abnormalities associated with Jews. For example, the Germans associated Jews with syphilis and an 'abnormal' flat foot.¹⁶ Both of these traits were associated with the inferior status of the Jewish 'race,' considered abnormal in comparison with the German norm. (Gilman 1991: 55) The Jewish man's flat foot¹⁷ was considered an atavism, a throw back to a less evolved race. This trait was linked to the origins of Jews, believed to be in Africa, and therefore a sign of their racial impurity, having mixed their 'blood' with Africans. (Gilman 1991: 49) The 'Jewish' traits were described in biological terms, as part of a social theory, but in some cases particular traits were considered a mark of his profession as a merchant, a symbol of urbanization. Urbanization was also a sign of degeneration. (Gilman 1991: 49)

¹⁶ That is, the Jew's 'abnormal' flat foot was contrasted with the 'normal' foot associated with Germans. (Gilman 1991: 55)

¹⁷ I will focus on the example of the 'Jew's foot,' as opposed to syphilis because the association with the latter 'disease' is rather complex (for instance, Jews were associated with the disease and considered responsible for spreading it, even though their incidence of infection was lower). (Gilman 1991: 96-101) ¹⁸ The 'atavistic' flat foot was only associated with Jewish men, not women.

Urban life was associated with the degeneration of 'races' not only in Germany, but also in other European countries. Social and physical pathologies were thought to be concentrated amongst urban dwellers. The city environment was considered unsuitable for healthy living and was thought to breed weaknesses. The consumption of alcohol and tobacco, along with the poor quality of the city air were thought to further the process of degeneration. (Pick 1989: 190-2) In these theories of degeneration, the degenerate traits were acquired through Lamarckian, rather than Darwinian, processes. It was not only those who willingly behaved in ways 'known' to lead to degeneration, who were at risk. Offspring, who would later become diffused throughout society, were believed to inherit the degenerate characteristics. The degenerates' social pathologies could also 'infect' others, either physically as in the case of sexually transmitted diseases, or slowly, by their influence over time, creating a degenerated or diseased city environment. (Pick 1989: 20-1, 190-1) Those people defined as 'degenerate,' often belonged to outside groups (of other nations, for example) or insiders of a society considered 'dangerous.' This latter example reflects the description of Jews by the Germans. As noted, the Jew's foot, considered a 'racial' trait, was also a symbol of urbanization, of degeneration. Degeneration theories provided a means of marking differences between groups, based on lifestyle and particular physical attributes. The emphasis on the physical and biological aspects of different groups reflects a new basis of degeneration. The concept of degeneration was not new in the 19th century, but previously it had rested within philosophical or political theories. Degeneration became a scientific and medical investigation in the 19th century, treated as an empirically demonstrable fact. (Pick 1989:

20-1) Many of the examples I have presented have been based on Germany, but racial hierarchies based on concepts of blood and heredity, and influenced by beliefs about degeneration, were widespread throughout Europe with different countries' theorists adding to and creating new theories.

In Britain, the stage was set for biological and racial theorizing about the innately deserving and undeserving by Thomas Malthus in the early 19th century. Though his fears of degeneration were based on differential rates of reproduction between the lower and upper classes, his 19th century successors would introduce into his theory of natural law, biological justifications for the categories of deserving and undeserving. (Chase 1977: 85) Among his successors were Francis Galton and Herbert Spencer who added the 'scientific' justifications to support the ranking of superior and inferior 'races' as well as the ranking of people according to the purity of their 'blood.'

Galton's theory of hereditary genius among the British upper class was based on his belief in their superior 'blood.' He published a book on this topic in 1869. Galton's claims were based on his observations that the children of the upper class were more likely to occupy professional positions. According to his theories, a hierarchy existed amongst the different 'strains' of Anglo-Saxons. The upper classes comprised the superior strains of the Anglo-Saxon 'race' and the lower classes and Irish comprised the inferior strains. Galton feared that the superior strains of the Anglo-Saxon 'race' were risking degeneration through poor breeding. That is, 'breeding' with inferior groups.

Even lower than the Irish were the other races found in the British colonies. Jews were also considered inferior 'stock' in Galton's ranking of human heredity. Based on these judgements and the 'problem' he identified in 'racial degeneration,' Galton proposed a solution: eugenics. The term is derived from the Greek word for "wellborn." Galton advocated racial improvement by "boosting the birth rate of the wellborn to the levels where they *speedily* prevailed over the less suitable strains or socially less wellborn classes." (Chase 1977: 12-14) The concept of Eugenics took hold in England and especially in the United States and Nazi Germany. The lesser known of the two latter cases is the United States where Galton's theory of eugenics had a direct influence on 20th century governments which used forced sterilization for seven decades as their weapon against "the menace of racial pollution." (Chase 1977: 15)

While Galton explained racial differences in terms of hereditary differences, Herbert Spencer framed these differences in terms of evolution. As the creator of 'Social Darwinism,' he proposed a theory of unilinear, human social or cultural evolution in which other races and subclasses were subordinated to his own class and 'race' (upper class, Anglo-Saxon). (Stocking 1968: 240) It was Spencer who coined the phrase, 'survival of the fittest.' He used his theory as a rationale for wasting neither time creating decent work conditions or living environments, nor money (in the form of wages or health care) on the lower 'stocks.' Though his theory was loosely based on Darwinian evolution, Spencer was a Lamarckian. Because of this, he believed that the differences between the races were an outcome of habits and lifestyles transmitted over many generations. (Stocking 1968: 239-40) Different dispositions, he claimed, had become

ingrained in distinct groups and created differences between the races. In order to prevent further racial degeneration, he recommended the selective 'breeding' of only those who had the inherited and acquired the 'fittest' characteristics of the upper class in order to produce a race of the super-fit. To address the 'problem' of the inferior races, he suggested an "exercise in pragmatic eugenics: he proposed that 'science' be used to select the best characters of the various inferior races and then breed them in scientific mixtures planned to salvage whatever rudimentary human worth was present in the two pooled hereditary endowments on the lesser breeds of humanity." (Chase 1977: 106-7)

Joseph Arthur de Gobineau has been called the "father of racist ideology." (Biddiss 1970) Born in France, Gobineau was a self-proclaimed bastard great-grandson of Louis XV. In Gobineau's hierarchy or evolution of the 'races,' he placed the Teutons at the highest end of civilization. The Nordics were the whitest of the white based on his ranking in which whiteness was associated with nobility, honour, the highest inborn qualities and most lofty destinies. Below the white race was the 'yellow race, followed by the 'black race.' Gobineau was also profoundly anti-Semitic. (Chase 1977: 90-91) In 1853 (to 1855) he published the two volumes of *The Inequality of the Races* (originally in French). In these volumes he outlined his scientific explanation of why the lower races could never achieve higher levels of civilization. The white race was naturally a distinct, superior and purer race, but he feared its degeneration as the Teutons' blood was thinned through the intermixing with inferior races (even among 'whites'). He believed that a study of the races was needed to prevent further degeneration of the 'white race' and "lower class horrors" such as democracy. (Blanckaert 1988: 49 – chapter 1 in Stocking 1988; Chase

1977: 90) Gobineau's writings had an immense impact when published and their influence lasted throughout the early decades of the 20th century.¹⁹ Chase suggests that American quoted Gobineau to defend slavery in the south, and "Europeans to rationalize the human costs of imperialism in the Asian and African colonies." (Chase 1977: 90) The German translation of his book appeared in a climate of growing conservative nationalism and increasingly political anti-Semitism. With hundreds of thousands of Germans already voting for anti-Semitic parties, "Gobineau's message of 'racial bastardization' being the root of many social problems 'gained an increasingly sympathetic ear." (Proctor 1988: 143 – chapter 5 in Stocking 1988)

These conceptions of superiority of 'blood' or heredity were incorporated into concepts of national identity. This was a decidedly unlike the kind of nationalism described by Herder. First of all, it was based upon biological rather than cultural characteristics of a nation. Secondly, the 19th century biological nationalism was based on an explicit ranking of nations according to the purity of their 'race.' This was particularly apparent in the case of Germany. Many German racial theorists picked up Gobineau's message and used it to prove the necessity of preventing further national degeneration through mixing with Jews. Houston Stewart Chamberlain (English by birth, he became a German citizen) was one of these theorists. He further elaborated Gobineau's ideas. An admirer of the overtly violent anti-Semitism in Chamberlain's writing was Kaiser Wilhelm. The defeat of Kaiser Wilhelm in World War I left Chamberlain in a state of profound despair for civilization. In 1923 Chamberlain also personally discussed his views with Hitler, who closely concurred with Chamberlain's ideas. (Chase 1977: 91-2) Another proponent

¹⁹ The German translation was published between 1898-1901 and the English translation in 1915.

of Gobineau's message was Ludwig Woltmann. Woltmann was the founder of the *Politisch-anthopologische Revue* in 1902, the leading publication for the Nordic supremacist movement. He was a tireless fighter for the Aryan and believed that the "preservation of 'Aryan blood' was the most urgent task of Sozialanthropologie. (Proctor 1988: 143 – chapter 5 in Stocking 1988) Eugen Fischer, one of the most influential anthropologists both before and during the Nazi period, described the goal of Sozialanthropologie as,

...'the preservation of our magnificent German people' against the combined spectres of venereal disease, alcohol, and the infertility of the upper classes. In 1917, he asserted that the 'racial degeneration' facing Germany – as evidenced by the growth of crime, prostitution, and mental illness – was not a fabrication of pessimists, but 'the binding consequence of naked facts.' (Proctor 1988: 144 – chapter 5 in Stocking 1988)

In this case the nation of the 'true' people of Germany is portrayed as jeopardized by racial degeneration through mixing with 'inferior races.' What class, culture and national divisions had accounted for was now explained in terms of race. (Stocking 1988: 7) Far from the cultural autonomy sought through 18th century nationalism, as described by Herder, German biological and racial nationalism set racial segregation as its goal. Economist Werner Sombart promoted this objective in his 1911 publication. At that time, he claimed that "Jews controlled or at least had a decisive influence on every aspect of national culture: art, literature, music, and theatre, and especially the major newspapers. This influence, according to him, was due to the fact that in general Jews were much more intelligent and industrious than the Germans." Jews' dominance and superiority was rooted in their 'blood,' and "it posed a problem that could not be ignored..." (Poliakov 1985: 11) Sombart did not think that expulsion would work, nor would assimilation, since, he believed, the racial mixing would be 'contrary to nature.' He mused, "Were not mixed marriages often sterile?" Sombart suggested a form of

apartheid, but his successors clearly went beyond his recommendations. (Poliakov 1985: 12) The Germans picked up on Galton's concept of eugenics and took it to an extreme form never reached in other countries, such as Britain and the US. In Germany, eugenics combined an extreme 'biomedical' vision (a vision that was scientifically unfounded) of racial purity with a totalistic political structure and proceeded from sterilization to excessive killing. (Lifton 1986: 24) The Holocaust is the most extreme example of a biological and racial nationalism known today. The memory of this atrocity has left its mark on beliefs about race and the role of biology in formulations of identity and nationalism.

Section iv: The crisis of national identity post-1950

The defining factors of national identity changed following the Second World War. The association of national identity with 'blood' (i.e. racial purity) or genetic traits was no longer considered acceptable. Social theorists (e.g. anthropologists including Franz Boas) disowned evolutionary theories, such as Social Darwinism, and science was used to emphasize the similarities between groups. Referring to the socio-biological and racist nationalistic theories existing prior to, and during the Second World War, Tom Nairn writes,

Certainly, as ideology all this was defeated alongside the Third Reich in 1945. As scientific explanation it has been repeatedly and utterly discredited by one revelation after another. None the less, its black shadow still affects all speculation in this area and for a long time more or less prohibited serious rethinking. (Nairn 1997: 10)

During the years around 1950, anthropologists and social theorists reframed national identity in terms of ethnic differences. Primordialist theorists, who had previously

explained nationality in reference to birth and race, now used the concept of ethnicity and felt obliged to make it clear that they disavowed all connection with the "old nonsense about race and inbred inequalities." (Nairn 1997: 10) In other words, the ethnic distinctions that were believed to underpin nationalism had to be cultural in their origins, and therefore 'reprogrammable' and changeable. Ethnicity could not be 'nature' in the "final-determinant sense beloved by Gobineau, Confederate slave-owners and Hitler." (Nairn 1997: 10)

According to Nairn, ethnicity remained the principle means of conceptualizing national identity until about 10 years ago, or as Nairn marks it, 1989. The people and organizations driving the national fissures in Eastern Europe at that time reintroduced the concept of 'blood' and biological nationhood into debates about national identity. Before examining Nairn's ideas on the biologization of nationalism, I want to say something about the concept of 'nationalism.'

Following World War II, the appropriateness of 'the nation' as a political unit began to be questioned. The political theorists espousing this view suggested that the concept of the nation was in decline and its disappearance was inevitable. (Bereciartu 1994: 154)²⁰ These statements were based on the observance of at least two challenges to national political units, one from the outside, and another from inside the nation. [1] The nation was believed to have shown its weakness through its dependence on other nations. [2] Ethnic minority groups inside the nation were increasingly claiming the right to their own

²⁰ Bereciartu's book was originally published in Spanish in 1986. He readily admits that his theories are Europe-oriented, much of his work focuses on the Basque.

political and cultural identity. These challenges were said to have "significantly weakened" the nation-state and "provoked a crisis of legitimation, and, in certain cases, real diminuation of the nation-state's political and economic power, since it has had to cede some of its jurisdiction to either supranational or infranational bodies or entities." (Bereciartu 1994: 149) Gurutz Jaurangui Bereciartu, a Spanish political theorist, claims that the,

technological revolution, the economic development stemming from it, and the universalizing of culture through new communications technologies are all provoking a need to reformulate the bases that sustain the present world political order, as well as a profound restructuring of the present political structures and institutions. (Bereciartu 1994: xv)

According to Bereciartu, the nation-state is one of the 'structures' that will either be significantly transformed by the changes described above, or it will disappear entirely. In place of the nation, he predicts that larger political units will be formed (such as Europewide conglomerations). (Bereciartu 1994: 178-9)

Tom Nairn does not believe that the nation-state has lost its place in the order of things. In contrast to Bereciartu, he claims that the 'national' has now proved to be more persistent than ever predicted. (Nairn 1997: 17) As 'proof' of the persistence of the national, Nairn refers to the fracturing of Eastern European nations in 1989. Though larger nations, such as the USSR, broke apart, internal nationalistic movements drove the fracturing. According to Nairn, the fracturing of the larger nations did not lead to the end of 'the nation,' as Bereciartu suggested, but to the creation of new, smaller nations. Nairn believes that the events of 1989 might indicate a mutation of nationalism, but he does not believe that nationality will be less important as a result. He suggests that other

political theorists read these changes differently, and that those people with "a certain style of wishful thinking interpret (the changes) as 'the end of nationalism." (Nairn 1997: 48) In his appraisal of the events, Nairn suggests that the concept of the nation as a political unit continues. If anything, the fissions of (previously) existing nations into smaller nations has led to an increased importance of the factors of nationality – ethnic, linguistic, biological and sometimes religious. (Nairn 1997: 48) He interprets the continuation of nationalism post-1989 as an indication that,

nationalism is not now and never was in the past a deviant or accidental departure from what 'should have happened.' It is no counter-current stream or side eddy, interfering with the majestic mainstream of Progress: nationalism is the mainstream, and its time we recognised the fact. (Nairn 1997: 48)

As noted above, Nairn believes that biology was reintegrated into the concept of nationalism when smaller Eastern European nations were formed. Because of this, he believes that when political theorists study nationalism, they must now deal with both the categories of [1] the nation as a political unit, and [2] the nation as a racial or biological group based on birth. Nairn believes that the life sciences and genetics will be of importance for future studies of nationalism. What he suggests these fields can offer to political theorists is an explanation of the relationship between biological and political nationalism. Since he believes that genetics and biology show that there is no straightforward relationship between these two concepts of the nation, he suggests that these scientific fields offer a 'great liberation' to political theorists. This 'liberation' comes from the elimination of the "dreadful simplicities" and "delusions" on which racism is based. (Nairn 1997: 13)²¹ This starting point opens the door to a study of "the prehistory and evolution of kinship (literal and metaphorical) which effectively links

²¹ Faye Harrison has critiqued claims that knowledge will prevent racist beliefs. What Harrison suggests will appear in place of overt theories such as social Darwinism, is a more subtle form of racism. (1995)

natus (birth) to nation" and nationalism. From this view then, nationalism is a central 'fact' of our existence and, far from the brink of extinction, is diffused through society and shaped by (as well as involved in the shaping of) many areas of life. Nairn's discussion of nationalism also chronicles the re-introduction of biological concepts into studies of nationalism. I will now move onto a discussion of the role of science, and specifically genetics, in modern claims of national identity.

Section v: The contemporary role of genes in claiming and creating a national identity.

Genetic sciences have developed significantly since the introduction of Mendelian genetics of the early 20th century. During the first half of the 20th century, 'races' were compared by analysis of blood types, which were transmitted according to Mendelian principles. Other hereditary traits were studied only in terms of their expression. Until the 1960s, when the chromosomal bases of Down, Klinefelter, and Turner syndromes were discovered, genetic studies were employed more for a comparison of hereditary traits (by the study of blood or by visible difference) than the genetic codes of humans (in terms of its clinical or diagnostic value)²². (Weingart 1998: 407 – chapter 15 in Finzsch and Schirmer) The 1960s also saw the introduction of prenatal testing followed by routine screening programs for 'inborn errors of metabolism' such as phenylketonuria, Tay-Sachs and sickle-cell anaemia. Once chromosomal differences could be distinguished, studies of genetic transmission of traits could focus on genetic similarities and differences that were not visible to the human eye. Over the past 20 years,

²² I am emphasizing the clinical and medical uses of genetics because this is the branch most relevant to control and identification of populations. The discovery of DNA, etc. added to a new understanding of humans, but less in terms of population studies.



knowledge within the field of genetics has exploded. This includes knowledge of the genetic make up of humans, plants and animals (e.g. DNA, RNA, etc), as well as knowledge for the practice of clinical genetics (e.g. screening for disease, genetic confirmation of maternity or paternity, etc.). Techniques for prenatal diagnosis, genetic screening, in vitro fertilization, and genetic engineering have advanced immensely. With a (rough) map of the human genome now available, resulting from the human genome project (HGP) initiated in 1990²³, a new level of genomic understanding has been reached. The efficiency with which genes for individual disorders can now be mapped is at least as important as the new knowledge. The availability of maps of the human genome means that anyone can access a version²⁴ in order to determine genetic linkages to disorders that they might be studying. This availability of genome maps is expected to greatly reduce the time and money needed for genetic research.

However, as we move into the 'post-genomic' era, the utility of the study of genes, in the sense of trying to discover 'the gene for' certain traits or conditions, is being questioned. (Woolfson 2001) Evelyn Fox Keller and Adrian Woolfson suggest that the assumptions that are used in the linkage studies described above (e.g. a gene leads to a protein) may be broken down over the coming years. (Woolfson 2001) For example, a deeper understanding of genetics means that scientists can no longer assume that if a deleterious gene is 'deleted' the expression of an associated unwanted trait will be prevented. Scientists have become aware of the redundancy within the human genome, meaning that

²³ Though a publicly funded group initiated the mapping of the human genome in 1990, a private research group, Celera, mapped it in parallel. The two groups published their findings together in February 2001.
²⁴ Any group can access the public map, but must pay a 'subscription' fee to access Celera's map of the human genome.

several genes may 'code' for the same trait. Fox Keller and Woolfson claim that if new scientific knowledge causes the break down of present assumptions in genetics, a major re-thinking of genetics research will become necessary. Common understandings of 'the gene for' will also be reconceptualized.

At this point though, in addition to the valuable scientific knowledge emerging from the field of genetics, it is believed that the potential for eugenic uses of this information is much greater than earlier this century. Given the basic linkage research, it is assumed that unwanted traits could be identified in utero, or diagnosed through genetic screening without the expression of the trait. (Weingart 1998: 408-10) Social scientists and genetic researchers have voiced fears of the misuse of genetic information. Scientists involved in genome-mapping research are worried about the potential uses of the information they have unveiled as well as about the use of knowledge uncovered in the future. Of particular concern is what to do with the concept of race. While they believe that their work has the potential to "deconstruct simplistic notions of race and ethnicity," they also acknowledge that stigmatization might also result. (Wade 2001) For instance, if an ethnic group, particularly a marginal one, became associated with a particularly 'bad gene,' this could lead to negative consequences for that group. (Williamson 1999: 75) Social scientists have raised concerns about the potential discriminatory uses of genetic data by insurance companies and potential employers. Some also fear the potential use of genetic technologies for eugenic purposes. Peter Weingart agrees with the view that there is no built-in barrier that would prevent medical genetic techniques from starting down the 'slippery slope' to eugenics. He suggests that barriers have to be erected from
outside of genetics, that is, by the political system. (Weingart 1998: 408) These barriers would delineate between eugenic uses of genetics and the medical uses, the former use being delegitimated by the barriers put in place.²⁵ But Weingart believes that there are other factors in today's society that will prevent eugenics movements from re-emerging in the pattern of the 1920s and 1930s. First of all, the scientific knowledge today has become more complex in its descriptions of human differences, emphasizing that the differences within ethnic groups²⁶ are larger than the differences between groups. This complex description "does not lend itself to the same primitive social categorizations for which it was used during the first half of the century." Secondly, the Western political context and social value system today rejects the unwarranted 'biologization' of social categories.²⁷

Weingart also asserts that the political sensitivity about eugenic uses of new genetic technologies is high. (Weingart 1998: 411) However, if significant social or economic problems arose in the US, for instance, affecting a socially, politically, or economically dominant class, he suggests that biological explanations or 'solutions' for the social or economic problems might be accepted. As Weingart claims, it is probably unavoidable "that laymen and policymakers alike tend to turn to biological explanations when social problems seem inscrutable." (Weingart 1998: 411) He mentions another possibility for

²⁷ There are notable exceptions to the rejection of 'biologizations' of social categories. In *The Bell Curve: Intelligence and Class Structure in American Life*, Richard J. Hermstein and Charles Murray argue for the biologization of social categories. Hermstein and Murray claim that biological factors determine African Americans' performance on IQ tests. The work of A. Philip Rushton is also an exception to the rejection of biologization of social categories.



²⁵ Weingart does not suggest that this line will be clear and easily drawn, but he believes that efforts must be made to set the two uses of genetics apart.

²⁶ These could be ethnic groups defined by a country of origin (but no longer of residence), but other groups could be included such as geographical resident groups (in Canada vs. Zaire or Norway), or groups based upon superficial physical traits such as skin colour.

the questionable use of genetic technologies. Unlike earlier forms of genetics, today's genetics are individualistically oriented. Weingart notes that the paradox of this situation is that although the new genetics are more 'democratic' and consumer-oriented, they may realize "the very eugenic ideals that the eugenicists of the early 20th century had in mind." That is to say, with the Western obsession for fitness and health, we may individually select against those traits found to be undesirable. This would be a new type of eugenics, and this time it would be "consonant with our value system, an outcome of individual choice within the population." (Weingart 1998: 412)

Genetics is being used in other, perhaps less dramatic ways that are consonant with our cultural ideals. One of these has been its appropriation for nationalist interests or goals. In several places around the world, including Iceland, Québec and Estonia, genetics have been used as scientific 'proof' of national identity. In most cases, particular genes, often related to mutations or disease, are being traced back to prove a common ancestry of a people, that is, the purity of their genetic heritage. These practices seem similar to the "Celtomania" of the 18th century that Herder criticized. As in that movement, Iceland, Québec and Estonia are involved in implicit ranking of nations according to genetic heredity and 'blood' – usually their own over others'. As outlined by Weingart, particular cultural and political systems lead to different uses of science. In these cases, economic and political factors have made suitable the use of genes in national identity. The objectives of each of these cases differ, but genetic nationalism is drawn upon in all three instances. It seems that concepts of 'blood' (as a symbol of racial purity, or ethnic purity, since the modern day populations of these groups are assumed to have descended

from the same 'founders') and 'heredity' (these populations are said to have inherited similar predisposing factors and traits) are being reintroduced into nationalism at the same moment. I will examine the cases of Iceland and Québec in greater detail to elaborate on these points in the third part of this paper.

Section vi: The role of anthropologists in racial research and anthropological reactions to this involvement

The theories of social scientists such as Spencer and Tylor, in addition to those of German anthropologists have already been outlined. Their positions on issues such as 'race' and eugenics are antithetical to those in contemporary anthropology. Yet at the end of the 19th century, their theories were consistent with the prevailing social and intellectual contexts. Tylor's comparison of physical and cultural traits of different 'races' was part of an attempt to bring the comparative method to the discipline of anthropology. The comparative method, used in the analysis of human groups (and their origins), had been pushed aside by polygenist theorists. The polygenist theorists, instead of comparing the similarities and differences of distinct populations, claimed the incommensurability of these groups because they were believed to be innately different races. Tylor's description of the social stages that different societies were believed to progress through on their way to civilization, has been described as an attempt to replace theories of degeneration of societies, with a theory of progress. Spencer's work reflects an attempt to introduce the biological theories of his day into a theory of social progress. (Stocking 1968: 118-9, 126-7)

A critique of the views of 19th century social scientists by anthropologists began at the turn of the century. American and British anthropologists rejected positivism and turned from evolutionary ideas. (Stocking 1988: 11) At this time, Franz Boas introduced a new direction of study for anthropologists. He chose to examine cultures in relativistic historical terms rather than in racial terms, countering claims about the inherently primitive physical aspects of certain races. (Stocking 1988: 10) Boas claimed that the "frequency distributions of most measured physical characteristics were substantially overlapping, and that the differences between different types of humans were small compared to the range of variation within each type." (Stocking 1988: 10) In an attempt to undermine beliefs about the unchangeable inherent qualities of different races (used by scientific racists to rank the 'races'), he suggested that it was possible for physical features to change according to their environment. To 'prove' his claim, Boas set up an experiment. His experiment involved measuring the heads of U.S. immigrants when they arrived in the States and how they changed over time. His results indicated that the formation of the human head was susceptible to change, based on environment, within a relatively short period.²⁸ His combination of anti-racist physical anthropology and historical relativism changed the trajectory of anthropology.

Boas' students were central to the adoption of a cultural concept in anthropology. Among his students was A.L. Kroeber. Kroeber argued for the importance of abandoning Larmarckian beliefs for the independent elaboration of the culture concept of societies. He attempted to rid anthropology of biological concepts, not because he believed that the

²⁸ Clearly Boas' experimental method was questionable in many respects, but it is the objective of his experiment that is relevant to this paper.

two concepts could not inform each other, but because he felt that the different areas of human existence that each discipline could shed light on should be fenced off from each other to avoid such aberrations as social Darwinism. Kroeber felt that this 'fencing' "could only be done on the basis of the prior development of the independent study of culture. And for this, it seemed necessary to burn all bridges between biology and the social sciences." (Stocking 1968: 268) One of the tactics that Kroeber suggested to eliminate anthropologists' reliance on racial concepts was by means of simple word substitutions: culture for race and cultural heritage for racial heritage. (Stocking 1968: 266) A. Montagu was also involved in efforts to remove racial concepts from anthropological theories. Before the end of World War II, he "took the bold stance that race is a dangerous fallacy and that the ethnic group concept has more heuristic value." By drawing upon advances in human biology and population genetics, he argued that "fixed, clear-cut differences do not exist between breeding populations or 'genogroups,' which differ only in the relative frequencies of one or more genes." (Harrison 1995: 53)

The historically relativistic, anti-racial concepts promoted by Boas and other cultural anthropologists did not convince all anthropologists and sociologists to convert from their race-based theories. Stocking points out that some social scientists continued to be influenced by evolutionary assumptions well into the 1920s and "certain were dazzled for a time by the promise of eugenics, 'the newest branch of sociology' in which some saw 'possibilities of race amelioration second, perhaps, to no other single science.'" (Stocking 1968: 267) Although the Boasian critique of 19th century evolutionary racism became increasingly influential during the interwar period, there were still struggles between

Boasians and racialists. Physical anthropology continued for some time to be carried on largely in traditional terms. Earnest A. Hooton and Carlton Coon continued their work in physical anthropology throughout the first half of the 20th century using quantitative methods to study human and animal variation as a 'scientific' means of ranking populations. Hooton and Coon, along with Boas, used craniological studies as a part of their quantitative method. Coon, a student of Hooton, created a 'great chain of being' of human and ape societies, composed of six levels which were reminiscent of older racial taxonomies of the 19th century. (Haraway 1988: 216-219 - chapter 6 in Stocking 1988) Though Hooton and Coon published papers criticizing racism and anti-Semitism within American and German societies (Hooton worked on a project at Boas' request to combat anti-Semitism in the US), their attitudes towards race and racism, as well as anti-Semitism have been described as ambivalent. For instance, although Hooton worked with Boas on certain projects, he also spoke at the Fourth National Conference on Race Betterment, which was organized by "the racist eugenicist Charles Davenport." (Barkan 1988: 186 - chapter 5 in Stocking 1988) Quantitative comparisons of societies were used by physical anthropologists in an attempt to remove qualitative judgements from the comparative method. But depending on the anthropologist employing the 'scientific' techniques, very different ends were reached.

Stocking suggests that it was difficult in the period preceding the Second World War to organize,

an anti-Nazi scientific consensus on matters of race and culture. But the mobilization of anti-Nazi sentiments in the war itself, combined with the revelations of the Holocaust, made it possible to establish a public scientific consensus on matters of race and culture. As much a critique of the claims of traditional racialism as a statement of positive scientific knowledge, it reaffirmed, in egalitarian liberal terms, the fundamental monogenism of the Western tradition. (Stocking 1988: 11)

Following World War II, studies of evolution and biology were marginalized, distancing physical anthropology from cultural anthropology. A firm 'scientific-cum-ideological' consensus against racism in 1951 made the study of evolution easier, but the rift that had developed during the interwar years between physical anthropology and the predecessor of modern social and cultural anthropology, remained in place.

Part II: Population genetics and the Human Genome Project

Section i: The concept of population genetics until the time of the HGP.

The field of theoretical population genetics emerged in the years between 1918 and 1932. The foundations of population genetics were built on mathematical models of 'breeding' populations and theories of equilibrium and selection of traits, which were developed in the first three decades of the 20th century. The outcome of this synthesis was 'classic' population genetics, a combination of Darwinism, Medelian genetics and biometry. (Provine 1971: ix, x, 131) These fields did not come together easily, however. In the early 20th century, two competing views of evolution were vying for scientific validation. On one side was Darwin, with his belief in gradual evolution produced by natural selection acting on small, continuous variations through generations. On the other side was Galton's belief in discontinuous variation. He did not believe that the small increments of change, described by Darwin, could bring about natural selection. (Provine 1971: x) Initially, the introduction of Mendel's theory of heredity seemed to support Galton's theory of discontinuous variations of traits between generations. The biometrists²⁹, who supported Darwin's theory of continuity in natural selection, were not interested in Mendel's theory because of its apparently discontinuous process of trait inheritance. (Provine 1971: 139) But a group of researchers, who had been impressed by Mendel's theory early in their educations, began to theorize about the ways in which Mendelian inheritance might be consistent with Darwin's natural selection. Ronald Aylmer Fisher, Sewall Wright, and J.B.S. Haldane would become the founders of population genetics through this new line of research.

While Mendel had restricted his research to the reproduction of self-fertilizing species, Fisher, Wright and Haldane began applying Mendelian research techniques to inbred populations, usually moths, guinea pigs, rats or mice. They mated animals both randomly and in accordance to experimental patterns. (Provine 1971: 145, 156, 169) Transmission patterns of simple traits such as colour of offspring quickly emerged from their research. However, oddities also appeared and the researchers had to account for unusual patterns of trait transmission.³⁰ For example, Wright's observed that the colour of guinea pigs' coats suddenly changed after 20 generations of inbreeding. He had already explained the 'normal' transmission of colour by gene-gene interactions. To explain these unexpected changes, he introduced the concept of random genetic drift. (Provine1971: 154-162) Wright's theories were compatible with Haldane's emphasis on genetic mutation in the process of evolution. (Provine 1971: 173) Fisher's concepts of additive and non-additive factors in genetic transmission provided an additional

³⁰ These researchers did not work together until later in life. Their initial explanations for certain aspects of inheritance and evolution were individualistic and their different views on these matters were never entirely reconciled. (Provine 1971: 178)



²⁹ Biometrists attempted to predict the transmission of traits between generations based on the principles of biometry.

explanation of how continuity of traits could be preserved through Mendelian inheritance patterns. He was central in uniting Mendelian genetics with biometric principles. (Provine 1971: 140-144) All three men had backgrounds in mathematics and biology. These disciplines were central to early population genetics and contributed the theoretical foundations of the field.

The discipline of population genetics has changed significantly since its emergence seventy years ago. New technologies and advances in medical knowledge have introduced innovative techniques as well as new ways of understanding hereditary traits. L. Luca Cavalli-Sforza, Paolo Menozzi and Alberto Piazza, in The History and Geography of Human Genes, outline the changes that have taken place in the field of population genetics. Human differentiation is now described in terms of gene frequencies rather than comparing traits. Cavalli-Sforza et al suggest that an analysis of at least 200 different genes is preferred by most experts in their field for the most accurate description of population differences (and similarities). (Cavalli-Sforza et al 1994: ix, x, 377) The ability to detect differences in the genetic traits of humans at a molecular level extends back to the early 20th century. The first example of genetic variation among humans was discovered by Karl Landsteiner in 1901, that of the ABO blood-group variations. But it wasn't until the 1950s and 1960s that the magnitude of molecular human genetic variation was understood. Many years passed until genetic comparisons could be made efficiently, i.e. until the techniques to test these differences were widely available, financially feasible, and could be performed within an acceptable period of time. (Cavalli-Sforza et al 1994: 3) In the early days of human population

genetics, data from physical anthropology, such as skin colour, body, skeletal measurements, and facial traits, were most often used, since they were the traits most easily viewed or the most common remains of past societies. While these studies yielded interesting information about human differences, temporally and geographically, there was a tendency among physical anthropologists and population geneticists toward ascribing the discrepancies to genetic causes when, more likely, the differences resulted from environmental disparities. (Cavalli-Sforza et al 1994: x, 4) A number of different domains are drawn upon to map population distinctions today, such as history, linguistics, anthropology, and archaeology, but Cavalli-Sforza et al emphasize that only genes "have the degree of permanence necessary for discussing fissions, fusions, and migrations of populations." (1994: x) The techniques for measuring genetic differences were developed quite recently. Analysis of the DNA of individuals only became possible in the 1980s, and the use of these techniques was still rare in 1994, but they were becoming more common. The authors describe the new techniques on the horizon in 1994 as having the advantage of being efficient, consistent and amenable to automation. Cavalli-Sforza et al looked ahead, in 1994, to the completion of the human genome project. They believed that it would become a useful tool to facilitate the identification of different populations. (Cavalli-Sforza et al 1994: 377)

Section ii: The promise of the HGP

The relative completion of the map of the human genome has led to changes in the fields of laboratory genetics research, clinical genetics and population genetics. A new era of genetics is being hailed in all these domains. Articles with headings such as: "Are you

ready for the revolution?" (in *Nature* magazine) predict the potential impact of new genetic knowledge and how it will influence future experimental genetics research. In this article, the focus is on how genetics will influence "systems biology." This field is based on mathematical analyses of gene and protein networks. The author believes that this field will become much more dominant now that a map of the genome is available, and foresees a time when it will be as important as traditional laboratory skills. (Butler 2001: 758-60) Another change in the field of genetics research is the new emphasis on single nucleotide polymorphisms (SNPs). SNPs are increasingly the target of research used to compare individuals' DNA and detecting mutations that may be associated with disease. (Stoneking 2001: 821) Scientists believe that the use of systems biology, or other new techniques created for genomic analysis, will be combined with new insights into genomic mutations to make linkage of the gene and disease possible. The potential impact of new technologies in this area also cannot be ignored. The more efficient the technology, the more likely it will be that these associations will be found. (Collins 2001: 542)

In terms of clinical genetics, and the way in which genomic information is predicted to affect self-perceptions, many scientists emphasize the humbling experience of realizing the small size of our genome and its unexceptional nature. (Pennisi 2001: 1178) One of the most significant aspects of this is the realization not only of our remarkable genomic similarity not merely to chimpanzees and other primates but also to nematode worms. It is now possible that the unique aspects of different communities can be compared to a normative map of the genome. An increased understanding of the distribution of different SNPs and particular proteins will increase scientists' ability to compare different populations at the genomic level, both to each other and to 'the genome.' For instance, different SNPs can be compared between different populations in order to determine how long ago different groups were part of the same 'mating population.' Since scientists can determine how long ago a SNP formed, they will be able to use the SNPs shared by two populations to ascertain how long ago the groups diverged. (Stoneking 2001: 821) SNPs may also be useful in identifying and comparing disease susceptibilities between different groups. (Wade 2001) Some scientists hope that a deeper understanding of human genetics, ushered in by the human genome map, will eliminate the "simplified theories of random drift" used by population geneticists. James Crow suggests that random drift theories have led to the neglect of the "disorderly complexity" that arises through human reproduction. (Crow 2001: 771)

Certain scientists describe the mapped human genome as a big step forward, while emphasizing that it is 'just a tool,' (Pääbo 2001: 1219). Other scientists are willing to reflect on much more far-reaching potentials of the genome map. One team suggests that the mapped human genome will lead to "deeper insights into functions of genes individually and collectively; fundamental biological and diseases processes; and ultimately improved diagnosis, prevention, and treatment of birth defects and adult diseases." (Nadeau et al 2001: 1253) Another scientist suggests that the new techniques of study, especially using SNPs, will "provide us with the power to uncover the genetic

basis of our individual capabilities such as mathematical ability, memory, physical coordination, and even, perhaps creativity." (Baltimore 2001: 816) Whether or not these goals will be reached is uncertain, but these statements illustrate the hopes what the genomic era (or post-genomic era of SNPs and protein analysis) will bring.

Section iii: Medical promise of HGP

To certain physicians and scientists, the completion of the human genome map represents an enormous amount of promise for the future of medicine. In the issue of *Nature* in which the map was published, one group of researchers claimed, "The complete human genome sequence will facilitate the identification of all genes that contribute to disease." Furthermore, "we propose that the functional classification of disease genes and their products will reveal general principles of human disease." (Jimenez-Sanchez et al 2001: 853) Close work between biologists and physicians will be necessary for these goals to be reached. Scientists and physicians alike believe that future genomic research holds a great deal of promise for complex, multi-gene disorders. In this area of research, scientists are particularly hopeful about what SNPs may have to offer. SNPs, even if not directly 'responsible' for a trait, can be used to locate genes that may affect that trait. (Stoneking 2001: 821) Scientists hope that the discovery of different SNPs will make it possible to predict individual risk factors for disease. (Collin and McKusick 2001: 540) It is also hoped that scientists will be able to use SNPs to create treatments for the identified disorders. The treatments for these disorders would theoretically include 'gene therapy' and new individually tailored "designer" pharmaceuticals. (Stahl 2000: 895) I emphasize the theoretical nature of these treatments because they remain highly

experimental (and sometimes dangerous)³¹ in the former case, and hypothetical in the latter case³². Francis Collins³³ and Victor McKusick predict that by 2010 predictive genetic tests will also be available for "as many as a dozen common conditions." They compare these tests to those already available for breast cancer and colon cancer. Individuals would be able to choose whether or not they wished to be aware of their susceptibilities and whether to draw on the interventions that might be available for their disorder. That is, the disorder for which an individual is diagnosed at risk. (Collins and McKusick 2001: 543-4)

Another area where scientists and clinicians see the human genome project contributing a great deal is in behavioural genetics. In the special issue of *Science* dedicated to the human genome project, an article entitled "Toward Behavioural Genetics" examines past research in this area and hypothesizes about future directions for this research. McGuffin et al explain that there are few diseases of this sort for which "a specific mutation confers the certainty of developing a disorder." Rather, behavioural disorders depend on multiple gene systems. The authors outline their research on a series of genetically complex traits in which they determined the influence of [1] genetic factors, [2] environmental factors, [3] nonshared environmental factors and errors of measurement. The traits studied were adult and child IQ, reading disability, personality, schizophrenia, major depression, autism, and hyperactivity. McGuffin et al found that by far, genetic heritability was the

Http://www.med.upenn.edu/ihgt/jesse.html

³¹ An eighteen-year-old participant enrolled in an experimental trial that attempted to use corrective gene therapy for the treatment of a rare liver disorder caused by a 'genetic defect,' died. The trial took place at the Institute for Gene Therapy of the University of Pennsylvania.

³² Collins and McKusick predict that individually tailored diagnostic methods and treatments will be available in the "next decade or so." (2001: 540, 544) ³³ Francis Collins leads the publicly funded human genome project research consortium.

leading factor in all traits. (McGuffin et al 2001: 1233) However, they point to a problem in these studies: the genetic factors underlying the traits are not identified. They note that there are many different genes influencing behavioural traits which confound the research because even if a gene is found, there are others involved and few having major effects. Contradictory results appear in behavioural research, at least partially because of this situation. (McGuffin et al 2001: 1234-5)

In the process of a literature review on a specific behavioural disorder, bipolar disorder, I found many conflicting reports regarding genetic susceptibility factors. Different groups found different 'bipolar genes.' These include the human serotonin transporter gene (Kirov et al 1999), chromosome 18p (Friddle et al 2000), and any one of 4p16, 12q23q24, 16p13, 21q22, Xq24-q26 (Craddock and Jones 1999; Morissette et al 1999). Other studies have linked bipolar disorder and schizophrenia to the same susceptibility locus, 13q32 (Berrettini 2000: 245), while others link bipolar disorder to the same genotype as unipolar depression (Morissette et al 1999: 570). In many cases research groups pointed out the weakness of their own results or others disproved their findings. For instance, Kirov et al emphasize that the effect of the serotonin transporter gene is likely small, with many other factors involved (Kirov et al 1999: 1249). A study by Vincent et al directly contradicts the Kirov et al findings, suggesting that such an association does not exist. (Vincent 1999: 137) Craddock and Jones note that a pattern is emerging from linkage studies indicating, "no single major gene exists that explains the majority of cases of bipolar disorder." (1999: 589) Other researchers have failed to find any significant linkages between genes and bipolar disorder and assert that in the history of this type of

research, "although >20 loci have been implicated, few of the data in these reports could be confidently distinguished from chance findings." (Friddle et al 2000: 205)³⁴

In an attempt to surmount the difficulties involved in finding susceptibility genes for behavioural traits, researchers have tried to examine the disorders from new angles. Ikonomov and Manji (1999) attempted to discover which genes might play a role in bipolar disorder by examining the influence of lithium treatment at the level of gene action. However, though they believe their results to be promising, they do not interpret them as conclusive. (1999: 1506, 1513) Evans et al (2001) explore a different issue associated with the introduction of many problems in psychiatric research. They focus their criticism on the fact that psychiatric diagnoses are based on "imprecise" phenotypes "mainly based on symptom profiles reported by patients." Additionally, there is a great deal of overlap between diagnostic categories creating a great deal of uncertainty in this existing classification system.³⁵ Evans et al point out that treatments in this field are largely empirical and the "causes of these conditions remain unknown." (2001: 35) They explain that many mutations in a number of different genes can result in a similar phenotype (36). The authors suggest that genetics is useful to psychiatry, but a major rethinking of phenotypes corresponding to genotypes needs to happen to make new findings more useful. In agreement with Evans et al, Seretti et al have emphasized the difficulties created by the fact that phenotypes do not guarantee biological homogeneity

³⁵ Leo Sher also points out the weaknesses of psychiatric classifications in his article "Candidate gene studies in psychiatric disorders: promises and limitations." (2001)



³⁴ This research group, among others, has found an association between bipolar disorder and chromosome 18, but they emphasize that while "each of these data sets provided statistical evidence reaching the suggestive level," none of them reached a "level recommended as being statistically significant." (Friddle et al 2000) Some further difficulties in researching complex inherited diseases are discussed in Gershon 2000.

including conflicting research results. (Seretti 1999: 204) Manji et al (1999) point to a similar difficulty that has appeared as a result of genetics research on bipolar disorder. They assert that there is growing recognition that bipolar disorder is likely a "heterogeneous group of disorders," and "the importance of identifying genetic, biochemical, or clinical predictors of differential treatment responsiveness or resistance has become increasingly appreciated." (Manji et al 1999: 29)

McGuffin et al believe that the human genome project can help scientists to move past some of these problems. They assert that it is crucial that multiple human genomes be sequenced to identify the several million base pairs that differ. It is these DNA variations that are responsible for the "ubiquitous genetic influences on individual differences in behavioural dimensions and disorders." (McGuffin et al 2001: 1235) They promote SNPs, whose identification will be facilitated by a comparison of human genomes, for their potential role in quickly identifying similarities among disease groups. Evans et al concur with value of SNPs for behavioural genetics research. (Evans et al 2001: 38) They are hopeful that the new "SNP Consortium," will promote further research in this area. To overcome the difficulty of apparent multiple phenotypes and genotypes for each disorder, McGuffin et al suggest that two approaches be used in conjunction with each other. One is a bottom-up approach focusing on particular genes and their products, while the other is a top-down approach which would focus on the behaviour of the whole organism and would investigate how "specific genes unfold in behavioural development and how they interact and correlate with experience." (McGuffin et al 2001: 1247)

Nick Craddock and Ian Jones suggest that new understandings of the genetics of bipolar disorder will make it

...possible to develop a rational, aetiology based classification of bipolar and related disorders which will almost certainly provide a much better guide to treatments and prognosis than do current classifications. A new generation of psychiatrists will learn not only to recognize clinical syndromes, as at present, but will be able to perform laboratory test that will help determine the pathogenesis of the psychopathology which in turn will guide the clinician towards the most appropriate therapy." (Craddock and Jones 1999: 592)

McGuffin et al extend their hope to the whole field of behavioural genetics. They believe that the human genome sequence will "revolutionize psychology and psychiatry," suggesting that "the most important impact will be on understanding the neurobiological basis of human differences and achieving a better grasp of the aetiology of diseases. The latter, in turn, should lead to the discovery of new and more specific drug treatments." (McGuffin et al 2001: 1249) They admit that the influence of environmental factors will remain a limiting factor in the "DNA revolution," but emphasize that overall the future looks promising.

Section iv: Commercial benefits of HGP

There are three principle areas in which companies are hoping to profit from the human genome project. One of the first areas of commercial ventures related to the human genome map was the service sector. The companies working in this area are involved in 'gene discovery' and information brokering, by selling "up-to-date information on genes and their products to companies searching for drugs and diagnostic tests." (Malakoff and Service 2001: 1194) Perhaps the most notable company working in the service area is Celera, the genomics company which raced the public sector's human genome project

consortium to the finish line – that is, to the completion of the human genome map. Other companies in this field include: Incyte Genomics, DoubleTwist, and Affymetrix. Incyte Genomics may move 'into the black' this year, but as of 6 February 2001 Affemetrix and Celera had reported losses of \$47-57 and \$92.7 million respectively. These losses have occurred despite Celera's high-powered sequencing abilities and their completion of a map of the human genome. Robert F. Service writes, "Like most biotech start-ups, the nearly-3-year-old company has yet to turn a profit. And, although the company's stock rocketed after going public in May 1999, its price tanked over the past year, along with that of other biotechs, from a high of \$275 a share to about \$50 today." (Service 2001: 1203) The economic viability of these companies is uncertain, particularly since the 'completion'³⁶ and publication of the human genome map. This publication does not bode well for service companies for at least two reasons. First of all, before the public consortium's map of the human genome was finished and became widely available, different companies were offering access to different numbers of genes. That is, each of the data banks of human genes they offered to clients was different, drastically different. Incyte Genomics advertised access to 120, 000 genes, including access to 60, 000 not available from other sources; Human Genome Sciences claimed to have identified 100, 000 human genes, DoubleTwist's claims ranged from 65, 000 to 105, 000; Affymetrix was selling DNA analysis chips containing 60, 000 genes. Since the completed drafts of the human genome each have roughly 30, 000 genes, this makes these companies' wares appear highly questionable – there seem to be far fewer genes than previously imagined, and already for sale. (Pollack 2001: C1, C4) The second

³⁶ The 'complete' drafts of the human genome announced by Celera and the public Human Genome Project Consortium are only drafts, with many regions of the genome still incomplete.

reason that the publication of the human genome threatens the viability of these companies is because, now that the public consortium is offering access to the human genome map free of charge, why would companies pay to see another version? This raises the issue of superiority claims for different maps of the genome. Craig Venter, head of Celera Genomics, claims that his company's map is far superior to that created by the public consortium. As proof, he states that some of the top scientific research institutions around the world are paying to use his map.³⁷ (Henderson 2001: 1, 5, 10) Even if Celera's map is initially considered superior, it is suggested that interest may lessen over time as the public consortium's map improves (they add to it almost daily). (Abraham 2001: A1, A7) The future of companies in the service sector is described by most financial commentators as uncertain.

The second type of commercial company trying to make a profit from the human genome and human genome project focuses on selling tools for the analysis of maps. These toolmakers sell the "machines, chemicals, chips, and computer codes that make it possible to sequence raw DNA." (Malakoff and Service 2001: 1295) The key to the success of these companies, suggest David Malakoff and Robert Service, is that, "like the peddlers who sold shovels, food, and blankets to gold miners – they typically demand payment whether or not their customers ever strike it rich." Several of these companies are reporting profits, for instance, Applied Biosystems made a profit of \$186 million in the year 2000. In order to remain profitable, these companies are already looking beyond the world of genomics and on to the world of proteomics, selling tools for the analysis of

³⁷ Sources have told reporters at *The Globe and Mail* that access fees to Celera's map are \$25,000 per scientist, with a minimum enrolment of 10 scientists per institution. There is some ambiguity over whether academic researchers must pay to use Celera's map.

proteins. (Malakoff and Service 2001: 1298) The commercial promise of these companies seems much more solid than that of the service providers.

The third type of commercial venture hoping to benefit from the human genome project focuses on creating pharmaceuticals using knowledge about identified human disease genes. It is predicted that in the long term, these companies will have the greatest payoffs of the three types of ventures described in this section. (Pollack 2001: C1, C4) However, initial investments required for this research are large and a 'blockbuster' drug is not a certain outcome. Companies have to go into debt, without hope of seeing profits for four to five years. (Malakoff and Service 2001: 1196-7) The human genome map is hoped to facilitate this research by revealing thousands of new targets for the creation of new drugs. PricewaterhouseCoopers, the largest "professional services organization in the world" (from their website,

www.pwcglobal.com/gx/eng/about/ind/pharm/phpressroomR&D2005.html), suggests that genomic resources hold a lot of potential for pharmaceutical companies, but only if they are selective about the genomic targets they introduce into research and development. This should be limited, according to PricewaterhouseCoopers, to only those targets having the highest commercial viability in order to prevent losing research funds on unpopular drugs. Once targets are selected, however, knowledge gleaned from the human genome project should greatly hasten the process of moving from genetic target to the final, tested product. (from PricewaterhouseCoopers' website; Malakoff and Service 2001: 1193)

Population genetics has been introduced into efforts to identify disease genes and create new treatments. Some scientists and entrepreneurs believe that the use of the genomes of isolated populations or those of groups believed to be genetically homogenous will facilitate this research by removing some of the 'noise' created by more heterogeneous populations. In the next part, I will examine two such projects, one in Iceland and the other in Québec.

Part III: Comparison of population genetics projects in Iceland and Québec

The population genetics projects in Québec and Iceland represent a new type of population-based study. By examining presumed genetically homogenous populations, they aim to facilitate the detection of 'disease genes.' They are based on the presumption that [1] 'disease genes' can be found for common, multifactorial disorders, [2] treatments can be created as a result of having identified these genes, [3] certain 'isolated' populations are genetically homogeneous, and that this homogeneity will facilitate the discovery of 'disease genes,' and [4] the 'disease genes' found to be responsible for a particular disorder will also be the genes responsible for this disorder amongst most or all other groups. Many of these claims have been challenged, casting doubt on what these projects will yield in terms of new understandings about the origins of diseases and in terms of useful treatments. Critics of these projects have also raised a number of concerns over the ethical foundations of population genetics projects. The critics suggest that due to the small size of the populations targeted by these studies, it will be difficult to maintain the anonymity of the research subjects. In the case of Iceland, it is suggested

that a limited amount of clinical information marked on a nameless genealogical chart of the country's population will enable anyone with access to this 'anonymous' genealogy of Icelanders (including scientists, outside 'subscribers' to deCODE's database, etc.) to identify many of Iceland's citizens. Critics of population genetics projects believe that deCODE should not be allowed to have exclusive control over the medical, genetic and genealogical databases of Iceland's citizens. They believe that this will give deCODE an unfair advantage over other researchers. Lastly, population genetics projects have been criticized for not appropriately obtaining consent from the individuals being studied. In Iceland, presumed consent is being used in place of informed consent. At a more general level, ethicists suggest that any research involving genetics raises difficult questions about how to obtain consent, since genetic information reflects on more than one person.

Between the challenges to the scientific foundations of these projects and the ethical concerns, there would seem to be many reasons for the people of Iceland and Québec to refuse to participate in the projects. However, in these two cases, and in the case of Newfoundland (the site of a similar population genetics project), the populations do not seem to share the concerns of the ethicists and critics described above. The populations of Iceland and Québec are generally supportive of the projects.

There are at least three reasons why Icelanders and the Québécois may choose to participate. Some people participate in these projects because [1] they are unaware that they are, in fact, enrolled in the projects or [2] they are unaware of the potential consequences of the research (e.g. the consequences of being identified as at risk for a

disorder 'known' to be associated with a particular family line). Other people participate because they believe that their participation may result in the discovery of treatments for locally prevalent disorders. A third motive for participation is a personal interest in learning about one's genetic lineage and a collective pride in a putative national genetic identity.

This third motive for participation seems surprising in light of the conscious removal of biological concepts from claims of nationality following the Second World War. However, it seems that in Iceland and Québec, the introduction of genetic studies into descriptions of national identity has not been a cause of surprise or concern for Icelanders or the Québécois. The genetic studies have been introduced in such a way that the new means of studying genetic lineages has been consonant with pre-existing genealogical research in Iceland and Québec.

Of the three reasons for the people of Iceland and Québec to participate in population genetics projects, it is the creation of genetic national identities in Iceland and Québec that interests me most as an explanation. I will develop all three of these explanations, focusing on the third, in the following sections of my thesis.

Section i: Population genetics in Iceland

Population genetics research in Iceland is more intensive than in almost any other place in the world today.³⁸ The project was initiated in 1996 by Kari Stefansson and is run by deCODE genetics, an Icelandic-owned³⁹ and -operated subsidiary of an American-based company. (Annas 2000: 1830: Chadwick 1999: 441: Stefansson 1998) Stefansson is currently president and CEO of deCODE. The Icelandic government signed a 12-year contract with deCODE genetics in February 2000, allowing the company to compile a database of the genealogies of all citizens of the country. This genealogical information will be matched to all existing medical information on Icelandic individuals. deCODE's records of an individual will be updated every Icelanders visit their physicians of have a laboratory test. The construction of a DNA database is also a part of deCODE's plans. (Coghlan 1998: 20; Gulcher and Stefansson 1999) This genetic database would supply deCODE with the information needed to link disease genotypes with clinical phenotypes, permitting them to track down 'genetic diseases.' (Kong et al 1999: 318) The licence runs for 12 years. After it expires, control of the databases (genealogical, clinical and genetic) will be passed back to the government of Iceland. The government is free at that point to do as it wishes with the databases. deCODE will pay the government \$1,000, 000 each year to cover the expenses involved the management of upkeep of the databases. It is expected that this will be a break-even endeavour for the government since it is estimated that it will cost at least \$1,000,000 each year to perform these tasks. (Greely 2000: 189-191)

³⁸ Similar projects are appearing around the world, Estonia is an example of a project quite similar to the project in Iceland. Anther project is beginning in Newfoundland, though this project is based on disease populations. The company running the project is very wary of giving out details regarding who will be included in their databases (presumably medical, genealogical and genetic).

³⁹ Icelanders own the *majority* of shares in deCODE Genetics.

deCODE's research is funded to a large extent (\$200 million has been promised) by the pharmaceutical company Roche, to whom deCODE has granted exclusive rights to information that may lead to the production of financially viable new pharmaceutical products or diagnostic tests. (Red Herring 2000) However, any new information produced from the database that is not economically interesting may be passed onto other Icelandic scientists to study. Information is considered to be economically interesting when it might lead to new pharmaceutical products or medical tests or treatments. Economically uninteresting information would include links between exercise, environment, or diet and particular diseases. This latter type of information would be unlikely to produce commercially valuable products. (Greely 2000: 176-8)

Iceland is considered to be an unusual and promising case for medical and genetic research because the government has kept detailed medical records of its citizens, since 1915. The government also possesses tissue samples of many citizens from as far back as 1945. Promoters of deCODE emphasize the relative homogeneity of Icelanders, claiming that the population has been virtually isolated since the 9th century when Norwegian Vikings arrived with their Irish slaves. They claim that this genetic homogeneity should make it easier to find the genes that lead to disease. (Gulcher and Stefansson 1999; Jonatansson 2000)

To enrol Icelanders into deCODE's project, informed consent has been bypassed in favour of offering citizens the choice to opt-out of the database. If they do not exercise this right, their personal medical records are automatically entered into deCODE's

database⁴⁰. Once they are enrolled, each time they seek medical attention in the future, their files will be updated at deCODE. The responsibility is placed on individuals to speculate as to how their medical information will be used. It is unlikely that all of deCODE's research plans are known to all Icelanders involved in the project. Furthermore, it is likely that deCODE's research plans will change over the course of their 12 year licence. Thus, most Icelanders and Icelandic physicians have a weak understanding of how their medical data will be used if they participate in the database. When speculating about how deCODE will use their medical information, Icelanders must also consider whether new information will be discovered about them that they would rather not know or have known by others⁴¹. All dead Icelandic citizens will be automatically entered into the database⁴². So even if an individual opts out, all information about their deceased parents or grandparents will be handed over to deCODE. Individuals cannot 'opt out' of the genealogical part of the study.

deCODE is trying to discover genetic risk factors for over 25 common disorders. (Gulcher and Stefansson 1999) The selected disorders have a high prevalence in many of the world's more affluent nations. The following priority groups of disorders are listed on deCODE's web site (www.decode.is):

- autoimmune diseases (including inflammatory bowel disease [Crohn's and

ulcerative colitis], psoriasis, atopy and rheumatoid arthritis)

⁴⁰Individuals can opt out before the database is up and running, preventing the entry of any of their medical data into the system or they can opt out after the database is in use. In this latter case, they can prevent any new data from being entered but cannot remove the data already entered into the database.

⁴¹For example, information about their parentage, susceptibility to disorders that have not yet expressed, and may never appear, etc.

⁴²In protest to this decision, Iceland's vice director general of public health was among the first to opt out of the database. (Dagur 2000; DV 2000)

- cardiopulmonary diseases (including asthma, chronic obstructive pulmonary disease, myocardial infarction, peripheral vascular disease and stroke)
- central nervous system diseases (including familial essential tremor, Alzheimer's disease, schizophrenia, anxiety disorder, bipolar disease, multiple sclerosis, narcolepsy, and Parkinson's disease)
- metabolic and other diseases (including osteoarthritis, non-insulin-dependent diabetes, osteoporosis, and endometriosis)

Inferring from this list of research priorities, it is clear that deCODE is focusing on multifactorial disorders rather than Mendelian disorders.⁴³ Many of the diseases being investigated fall into the chronic, as opposed to acute, category of disease. They are also diseases generally associated with populations with an average long life expectancy.

The different groups involved in the organization of this project have overlapping goals. deCODE is concerned with making a profit from their work. Roche is hoping to recover the money they have invested in the project as well as making a profit from new pharmaceuticals created from the project⁴⁴. Like other pharmaceutical companies involved in this type of research, Roche is hoping to create a new 'blockbuster' drug.⁴⁵ In the long term, the government of Iceland is hoping that knowledge of its citizens' genetic predispositions to disease will assist in reducing the cost of providing health care for Icelanders (the country's health care system is public). deCODE believes they can

⁴³ Multifactorial disorders are those that involve many genes interacting with each other to produce an effect. Multifactorial can also be used in a clinical sense to refer to disorders involving multiple genes interacting with each other and their external (e.g. social) environment. Mendelian disorders are associated only with one gene of major effect (e.g. someone could have *the* gene for sickle cell anaemia).
⁴⁴These claims are based on the content and promises found on the financial pages of their websites.

⁴⁵ The term 'blockbuster' designates a drug that has become the financial backbone of a company. The most obvious example is Prozac, which has been a major source of revenue for Eli Lilly since its appearance in 1987.

help the government reach this goal by creating genetic tests for a wide variety of disorders. This would theoretically allow early detection of disorders or enable a physician to better understand a patient's risk before invasive steps are taken. (Gulcher and Stefansson 1999) How and when they will be able to reach these goals is unclear. (Associated Press, CNN [Europe], April 2001)

Section ii: Population genetics in Québec

In Québec, a group holding a genealogical database for a portion of the province's citizens organizes the population genetics project. This group also holds historical data on the population of Québec extending back to and beyond the 'founders' of the Saguenay / Lac-St-Jean regions. This project is operated by a set of academic researchers whose work is held accountable to the public and whose research is supported by public funds. The research was initiated by IREP (Institut Interuniversitaire de Recherches sur les Populations) at the Université de Québec à Chicoutimi in 1972 and has been headed throughout this time by Gérard Bouchard, a historian and sociologist. (Gradie et al 1988: 322) Originally it was a historical study with the objective of creating a tool to investigate the migration patterns and founders of the population near Chicoutimi. The specific region being studied was the BALSAC region, taking in the area of Bas-St-Laurent, Saguenay, and Lac-St-Jean. The population of this region is said to have descended from inhabitants of Québec's Charlevoix County following migration from this region. (De Braekeleer 1991: 141; Gradie et al 1988: 322) Historians have established that ancestors of the Charlevoix County population in turn came from

northwestern France in the 17th century (the majority of these founders came from Normandie, Ile-de-France, Poitou, and Aunis [Heyer et al 1997: 212-14]). (De Braekeleer and Dao 1994; Heyer 1995: 1451, 1454; Heyer 1997: 101) IREP is in the process of extending the database to all of Québec. (Bouchard 1999: 11; Bouchard 2000: personal communication)

The IREP research group is in the process of moving their offices to Montréal (Université de Montréal). Bernard Brais, a professor at Université de Montréal, has been named the new director of the research group. (Brais and Bélanger 2001) IREP has made no plans to create a genetic database – the project will be limited to a genealogical database that will be accessible to outside researchers investigating specific diseases. (Bouchard 2000: personal communication) IREP's genealogical database caught the attention of scientific researchers in the early 1980s because it contained information on 'pure laine,' literally 'pure wool,' Québécois. The 'pure laine' Québécois are those people whose ancestors are believed to have arrived in Québec early in the process of colonization. Because these people were often quite isolated in remote, small villages for many generations, they are believed to share a number of hereditary features. This makes them interesting to scientific researchers and, over the years, the genealogical database has been opened up for use by scientific researchers in an attempt to better understand the transmission of diseases of high prevalence in the region. Scientific researchers must submit a proposal for their project and, if accepted, IREP will provide them with specific genealogical information they have requested.⁴⁶ (Bouchard 2000: personal communication; De

⁴⁶ Scientific researchers generally provide a list of patients' names to IREP, and IREP returns information on the ancestry of these people as well as their contemporary relatives.

Braekeleer 1991: 141, 143) This research began with unifactorial disorders, but was gradually opened up to multifactorials. Researchers currently using the database are investigating diseases in the general population of North America (e.g. osteoporosis and hypertension). This represents a shift of IREP's original goals. When the database was first made available to scientists, IREP's objective was to use the genealogical database as a means of studying diseases of high prevalence in the BALSAC region. (Morissette et al 1999; Vezina et al 1996, 1999)

When scientific researchers use IREP's database, their starting point is a list of patients enrolled in a particular study. For instance, this could be a group of patients enrolled in a genetic association study on bipolar disorder. This list of patients would be passed over to an IREP researcher. The names would be entered into the genealogical database in order to construct individual family trees of the patients. These family trees would include a patient's ancestors extending back to the founders of Québec, if possible. Some lineages have also been traced back to specific ancestors in France. Each patient's family tree would also include all their contemporary relatives traced as descendents from a common founder of the lineage. The contemporary relatives found through this process are considered potential carriers of the same 'disease gene' held by the patient population enrolled in genetic research. In other words, the patient's contemporary relatives are considered to be at risk of developing the patient's disorder.

IREP stringently observes confidentiality and access to the genealogical database is strictly controlled. (Bouchard 2000: personal communication) Even though IREP does

not hold any genetic materials, their collaboration with outside scientists, combining genetic materials with their genealogical database, allows scientists to study the transmission of genetic materials over the course of generations. This makes the outcome of IREP's collaborations similar in many ways to the outcomes of projects in Newfoundland and Iceland.

In order to gather the information to create the database, IREP was able to bypass the process of obtaining consent of the individuals involved. In the case of the data drawn from the 19th century, it was clearly not possible to request individual consent. Before 1993, vital statistics for the population of Québec belonged to the province. These circumstances facilitated the collection of genealogical data on the Québécois. In 1993, in the civil code was changed and genealogical information became private and confidential. From 1993 onwards, IREP resorted to the use of a Québec law that allows researchers to use vital data without consent. (Bouchard 2000: personal communication – specific law not described) When the database is used for medical genetics (to match genetic samples with genealogical information), consent is required either from individual patients or from the director of scientific research on a specific project. The researchers' protocols must pass through the ethics committee of the university they are working with, and because of this, the decision about whether to contact at risk individuals is left to researchers outside of IREP since it is they who create the protocol.

As noted, use of IREP's database is open to any researcher who applies, provided that their proposed work meet IREP's ethics criteria.⁴⁷ Research priorities for genetic studies are set according to applications submitted to IREP and therefore driven by the interest of the scientific community. (Bouchard 2000: personal communication) Studies have been published on a variety of disorders, including bipolar disorder (Morissette et al 1999), cardiovascular disorders (Couture et al), and Alzheimer's disease (Vezina et al 1996, 1999), among others.

The goals of this group are multiple and their priorities have shifted over time. IREP's initial goal was to construct a genealogy of Québécois to better understand the BALSAC region's demographic trends, family structure, reconstruct family lines, trace social histories and social institutions, and to examine the impact of founders on a limited population. In the 1980s, the group's interests and goals moved toward understanding diseases that, according to scientists studying the disorders, seemed to be linked to the genetic mutations in the BALSAC region. IREP's goals have now broadened to an interest in genetic disorders within the general population, and their interest is to further scientific understandings within genetic research. The history of the Québécois remains a priority for IREP. (Bouchard 2000: personal communication)

⁴⁷ These criteria change over time in order to remain flexible enough to work with a broad range of researchers.

Section iii: Scientific goals and challenges to the scientific basis of population genetics research

In Part II, section ii, I outlined many of the medical breakthroughs that have been predicted by scientists to arrive as a result of the human genome project (HGP). Population genetics projects are hoping to capitalize on the new information available from the HGP and to benefit from the new technologies created for this research. Any researcher studying the genetic bases of disease can draw on the tools and information produced as a result of the HGP. This type of research often uses a clinically based sample of patients who are likely to be heterogeneous and multicultural, especially when the patient populations are drawn from large cities. Researchers affiliated with the population genetics projects in Iceland and Ouébec claim that they have an advantage over the researchers using clinically based populations because of the data they have access to. The researchers affiliated with the population genetics projects claim that access to a genealogical database provides greater knowledge about members of the population who might be affected with a particular disorder. This at risk population would be available for testing in order to determine whether or not they shared a particular 'disease gene' with the afflicted patient population. Population genetics research is believed to inform researchers about how widely a gene is shared and how often it 'expresses' itself. That is, how often a person carrying a 'disease gene' will be afflicted with the disease and how often they will remain disease-free.⁴⁸ It is also believed that access to clinical medical records would also benefit the researchers

⁴⁸ In Iceland, this type of association study would be greatly facilitated by the DNA database. Genetic association studies could be performed without obtaining individual consent or by going through the process of collecting DNA, since deCODE would already have individuals' samples in their databank. In Quebec, association studies investigating at risk groups would require a scientist obtaining consent to contact these people. At this point, individuals would have the right to provide DNA samples or not.



affiliated with population genetics projects. (Kong, Gulcher and Stefansson 1999: 578)⁴⁹ The second advantage claimed by researchers affiliated with population genetics projects is the presumed genetic homogeneity of the populations being studied. Because of this homogeneity, it is believed that when searching for specific genes, there will be less 'noise' for scientists to search through in their genetic codes. It is believed that this feature of the Québécois⁵⁰ and Icelanders will facilitate genetic research. (Morissette et al 1999: 568)

Despite the apparent benefits of population genetics research for investigations into the genetic origins of disease, several assumptions that underlie this kind of research have been attacked. deCODE's research methods have been challenged by independent researchers who claim that, despite the large amount of data available to deCODE, the techniques and assumptions underlying the company's approach are inappropriate. Critics of deCODE claim that the company's research will not be successful because it is premised on a unifactorial model of 'disease-gene hunting.' J.H. Edwards, a professor of genetics at Oxford University who studies the genetic basis of schizophrenia, suggests that deCODE's attempts to find 'disease genes' will not be useful in the case of multifactorial disorders. deCODE's method, which is based on finding the 'disease gene' associated with a particular disorder, will not allow them to discover the factors that bridge the gap between gene and body, or gene and mind, in the case of deCODE's

⁵⁰ IREP's researchers, while they believe the 'pure laine' Quebecois to share certain genetic traits, do not claim that the Quebecois are as homogeneous as, for example, Icelanders are.



⁴⁹ Augustine Kong is the director of statistical genetics at deCODE, Jeff Gulcher is the vice president of research and development (in addition to being a former PhD student of Stefansson), and Kari Stefansson, as previously mentioned, is the chief executive officer of deCODE Genetics.

research on mental disorders. In other words, the disorders being researched are too complex to be accounted for by deCODE's research methods. (Edwards 1999: 1353)

Regarding the presumed genetic homogeneity of the populations in deCODE's and IREP's work, as noted, these researchers claim that their work is facilitated by the fact that the genomes of Icelanders and 'pure laine' Québécois are more similar to each other than the genomes of people in, for instance the US, or large cities in Canada. According to researchers at deCODE and affiliated with IREP, the homogenous character of the Québécois (de Braekeleer and Dao 1994: 236; Morissette et al 1999: 568) and Icelanders (Stefansson quoted in Trivedi 2000) helps to reduce the 'noise' that researchers must work through to isolate particular disease genes. The homogeneity of the 'pure laine' Québécois and Icelanders has been challenged. It is commonly believed that the population of Iceland has descended from a small group of Norwegian Vikings, and that the homogeneity of Icelanders has been maintained through a series of catastrophes that greatly reduced the population several times in Iceland's history. But this story has been questioned. Edwards and others suggest that Iceland was settled by a diverse group of people, including a substantial number of Celts. This would increase the genetic diversity of the founding population. Furthermore, these same commentators suggest that the 'catastrophes' in Iceland's past have not been significant enough to reduce the genetic diversity of the population. Finally, these critics also challenge the presumption that Icelanders have been isolated throughout their existence, and cite evidence of the immigration of French fishermen into Iceland. (Arnason n.d., letter to editor; Edwards 1999: 1353; Trivedi 2000) Icelandic researchers published a report in August 2000 in
which they compared the genetic markers of Icelanders with other Europeans. They found that Icelanders are among the most heterogeneous of Europeans, more so than the French. (Arnason et al 2000: 373-4) deCODE's scientists quickly launched a rebuttal that was intended to re-establish the genetic homogeneity of Icelanders. (Stefansson quoted in Trivedi 2000) The dispute is unresolved and the genetic homogeneity of the Icelanders remains ambiguous.

Claims have also been made for the genetic homogeneity of 'pure laine' Québécois. (de Braekeleer and Dao 1994; Morissette 1999)⁵¹ The pure laine Québécois are those who are thought to be descendents of the original groups of settlers who came from France. Many of these 'pure laine' Québécois live in the Saguenay/Lac-St-Jean region of Québec. Genetic studies of mitochondrial DNA and unusual disease genes have been used to trace these Québécois' ancestry back to origins in specific regions of France. Mitochondrial DNA is genetic information passed unaltered, except in infrequent cases of mutation, from mother to daughter. This type of genetic information has been used by other researchers to trace the origins of maternal lineages 25,000 years into the past.⁵² Other researchers have suggested that the ancestors of the 'pure laine' Québécois have intermarried and become genetically associated with Amerindians and the English in Québec. (Bibeau 1995: 171) The ties between these communities have not been reflected in IREP's studies of the genetic history of Québec. Many factors would explain the

⁵¹ Many other studies published by IREP researchers focus on the similarity of pathological genes among this population. (de Braekeleer 1991; Gradie et al 1988; Heyer 1996; Heyer 1999; Heyer et al 1997) The shared genetic traits of the 'pure laine' Quebecois are believed to have resulted from the 'founder' effect. These researchers claim that the genetic composition of 17th century founders of Nouvelle-France (Quebec) is still reflected in this group of Quebecois.

⁵² Bryan Sykes, a British geneticist, recently published *The Seven Daughters of Eve*, in which he traces the origins of different European lineages. (Kanigel 2001)

mixing of the French population with other groups. For instance, the gender division of the 17th century founders of Nouvelle France included 1710 males and only 918 females (Heyer et al 1997: 212). IREP's studies have not addressed possible mixing of the French settlers with others. I have contacted IREP to inquire whether they had ever examined the possibility of shared genes between Amerindians and pure laine Québécois. I was unsuccessful in my attempts to receive confirmation as to whether any such research has been performed. (Personal communication 10 May, 25 May, 30 May 2001) As in the case of Iceland, it seems as though popular stories about the genetic homogeneity of Québécois are used subjectively and instrumentally in order to create the image of a homogeneous and unique population.

Population genetics studies also assume that, [1] the isolation of 'disease genes' will lead to the creation of treatments. It has been much more difficult to find treatments targeting 'disease genes' than previously imagined. Many pharmaceutical companies are finding themselves investing large sums of money without seeing significant results – profits are only forecast for at least five years from now. (from PricewaterhouseCoopers website: www.pwcglobal.com/gx/eng/about/ind/pharm/phpressroomR&D2005.html) Others believe that this process could take decades. (Associated Press 2001)

Section iv: Concerns about the management and operation of population genetics projects

Ethicists and physicians around the world have raised concerns about certain aspects of population genetics projects, especially in Iceland. Some of these concerns are specific to Iceland, such as the use of presumed consent rather than informed consent, and the

granting of exclusive rights to information to one company in this specific project.⁵³ (Chadwick 1999: 443; Greely 2000: 176-190; McInnis 1999: 235, 238) Other concerns apply to almost any population genetics project. For instance, a broad set of concerns has been raised regarding the ways in which the results of genetic tests might be interpreted. Concerns has also been expressed over the potential for discrimination based on 'bad genes.' (Greely 1998: 480, 495; Mauron 2001; Sommerville and English 1999; Williamson 1999: 75) I mention these ethical concerns, neither to support nor dispute them, but because these issues have been highly publicized by ethicists, physicians and deCODE's opponents. The publicity surrounding these ethical concerns has likely contributed to Icelanders choosing to opt out of deCODE's project. However, only 7% of Icelanders have made this choice at this time. This would indicate that there must be other reasons for Icelander's willingness to cooperate with deCODE.

Section v: Reasons for participation in population genetics research and the creation of genetic nationalism

When considering the amount of trust Icelanders are putting into their government and into deCODE, Eliot Marshall, a journalist for *Science* magazine, writes, "It's hard to imagine any U.S. agency being entrusted to keep so much volatile information in one database – medical records, genetic test results, and family histories going back a millennium." (Marshall 1998) Why is it that the people of Iceland and Québec participate in these studies? I believe there are at least 3 explanations.

⁵³ There are many other contentious issues surrounding deCODE's work. For instance, all dead Icelandic citizens will be automatically entered into the database. So even if an individual opts out, all information of their deceased parents or grandparents will be handed over to deCODE. Individuals cannot 'opt out' of the genealogical part of the study. As a result of this decision, Iceland's vice director general of public health was among the first to opt out of the database. (Dagur 2000; DV 2000)



The first, and perhaps most obvious, explanation is that the individuals involved in the research either are unaware of the projects or they do not understand the significance of the studies in the absence of media attention or oppositional organizations. In Ouébec, due to the low profile of the project, it may that individuals do not know they are a part of a constructed genealogy since consent in these research projects is only requested at the time that biological samples are collected.⁵⁴ Individuals may also be identified as at risk for particular diseases without their prior knowledge of specific research. That is, they may be identified as a distant relative of a patient enrolled in a genetic association study. Whether genetics researchers contact at risk individuals to inform them of their chances of carrying a 'disease gene,' is left to the discretion of the researchers running the experiments. In Iceland, it is unlikely that many people are unaware of the project. However, only 13% of Icelanders considered themselves to have a good grasp of the bill, according to a Gallup survey in November 1998. (Andersen and Arnason 1999: 1565) This is not surprising given the broadness of the terminology of the bill and the "less than clear objectives." (McInnis 1999: 235) The poor understanding of deCODE's research objectives may result in Icelander's participation in the project. This would not be as a result of their acceptance of deCODE's objectives, but because they do not understand particular implications of deCODE's research. A complete understanding of the implications of deCODE's might lead to their withdrawal from the project.

⁵⁴ This information is true to the best of my knowledge. There are likely loopholes I am not aware of (Bouchard, during my interview with him, alluded to at least one case in which individuals can be enrolled into a genealogical analysis by a research director, so it is possible that some people may not be aware of the full extent of the study they are involved in).

A second explanation is that people participate in this research because of their interest in locally significant disorders. Individuals suffering from one of these disorders may participate with the hope that a treatment or cure may result. Individuals may also participate to learn if they are at risk for or potential carriers of one of these disorders. Researchers working on one of these disorders (or physicians treating afflicted patients) may encourage participation in these population genetics projects because the projects offer a rare chance to learn more about local disorders.⁵⁵ This explanation may account for another subpopulation of the participants, but I believe that there must be at least one more explanation to account for the interest and even eagerness of many of the participants and organizers of this research. (Greenwood 2000; Specter 1999: 50)

The third explanation for Icelanders' and Québécois' participation in the population genetics projects is based on the existence of a new type of collective identity within these two groups, genetic nationalism. The concept of the genetic homogeneity of Icelanders and Québécois has been used by researchers at IREP and deCODE to create a sense of genetic nationalism. Einar Arnason, an opponent of deCODE Genetics, claims that Kari Stefansson has promoted genetic nationalism to secure participation in population genetics projects. Icelanders have presumably become interested in genetic nationalism because it allows them to gain a greater understanding of their ancestors and of the 'unique' nature of their people. By participating in deCODE's project, genetic research likely represents a new tool to trace genealogies, which was already an

⁵⁵ In all the cases presented in this paper, the healthcare systems are public (i.e. receive low levels of funding) and research funding for rare disorders affecting only a relatively small population is scarce (especially from the private sector).



established practice in Iceland before deCODE existed.⁵⁶ In Québec, there is a political element to genetic nationalism, in terms of the people running the project and the people participating in it. I will now present these arguments in greater detail.

In Iceland, in order to evoke a sense of genetic nationalism, an imagined genetically homogenous community has been created. In making this claim, I have drawn upon Benedict Anderson's work on imagined communities (1991). According to Anderson, the nation is an imagined community because. "the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion." (Anderson 1991: 6) Similar to Anderson's concept of the national imagined community, the 'genetically homogenous' imagined communities of Iceland and Québec will never have a complete knowledge of their fellow members. Yet, these communities are portraved by themselves and by IREP and deCODE as distinct national groups, joined by their similar genomes. In Iceland, the homogenous nature of Icelanders is imagined because their homogeneity is not known in any real way⁵⁷ at this point in time, and it is possible that it will not be determined in the future.⁵⁸ (Anderson 1991: 6) The belief in their genetic homogeneity gives Icelanders more a means of 'knowing' about themselves and each other, rather than 'hard evidence' of their genetic codes. The 'uniform' genetic character of Icelanders also gives them a new and scientific means of distinguishing themselves from others. Stefansson has

⁵⁸ At this point, I am referring to the dispute between Arnason et al and deCODE's scientists as to which genetic markers truly reflect a population, and can thereby be used to determine the real degree of genetic homogeneity of a group.



 ⁵⁶ In the case of Iceland, and from the point of view of Kari Stefansson (not necessarily that of all Icelanders), this new sense of identity might also be called commercial genetic nationalism.
⁵⁷ That is, their genetic homogeneity is not clearly demonstrated every day.

promoted the homogenous community of Iceland as valuable because of their 'pure' genomes, implicitly contrasting them with the impure genomes of others. Stefansson has likewise disseminated stories of Icelanders' origins in his writings and claims to have 'proven' these through genetic studies. Icelanders' origins are a part of a heroic founding story, with aristocratic ancestors (in some versions of this founding myth, the original Icelanders came from Norwegian nobility), endurance through catastrophes (such as plagues, earthquakes, volcanoes), and survival "in accordance with Darwinian principles." (Jonatansson 2000: 38) Jonatansson claims that this history has led to the remarkable and unusual character of today's Icelandic population. And, "according to scientists, the Icelandic population reflects the gene pool of Northern Europe as it existed in about A.D. 800." (Jonatansson 2000: 38, citing Stefansson and Gulcher)

The Icelandic population has been characterized in ways that follow older concepts of 'blood,' that is, the purity of the line of a people. Icelanders have also been characterized in terms of genetic heredity, i.e. similar traits associated with a particular group of people. In deCODE's genetic testing, these two traditionally separate means of understanding the composition of groups have converged. Genes are being used to 'prove' the purity of Icelander's lineage as well as to trace the passage of hereditary traits existing now as well as in the past. The choice of traits used to 'prove' Icelander's lineage is interesting. 'Disease genes,' that is, markers of pathology, are being used to positively identify Icelanders as a group. One example is the BRCA2 gene. Icelandic researchers claim that the genetic mutation of this gene has been passed down to contemporary Icelanders from one particular Icelandic ancestor, Einar, a 16th century cleric. (Specter 1999: 40) This

mutation is now claimed to be at the base of virtually every case of hereditary breast cancer in Iceland today, marking today's carriers of this gene as descendants of Einar. This means of identifying a group based on pathological features recalls the prejudices of 19th and early 20th century Germans who marked Jews as carriers of particular pathologies. What is interesting about the use of this means of identification in Iceland is that pathology is not being used to stigmatize outsiders, but to confirm the majority group's identity. 'Real' Icelanders share the same genetic mutations.

The type of genetic nationalism that exists in Iceland is clearly biological and does not draw upon cultural attributes of Icelanders. It does not draw on the language or traditions of Icelanders, but their physical bodies. Einar Arnason has suggested that Stefansson first created a sense of genetic nationalism among Icelanders and then used it to dupe the people of Iceland into participating in his project. While Stefansson's promotion of Icelandic DNA and the purity of their genealogy might have increased awareness of the genetics involved, Icelanders already had a great deal of pride in the 'blood' of their people. The hobby of genealogical analysis was ubiquitous throughout Iceland prior to Stefansson's promotion of the genetic identity of the population. While population genetic studies in Iceland might have created a sense of genetic nationalism, the effect was only to add a hereditary (genetic) element to Icelander's pre-existing national identity based on 'blood.' Because of this, it would be inaccurate to claim that the Icelandic population was 'duped' into participation. That is not to say that they are completely aware of the consequences of their participation (the consequences remain unknown to most, even to medical practitioners in Iceland), but that their willingness to

participate is based both on a newly created genetic nationalism and their own desire to instrumentally use genetics to add to their knowledge of their country's genealogy. Genetic nationalism might have been useful in drawing Icelanders into deCODE's project. However, it was not simply a matter of Stefansson tricking Icelanders into participating in his research. The studies that deCODE has made available on the genetics of their ancestors offered a valuable tool to Icelanders that has provided further support of their already celebrated collective identity.

In Québec, genetic nationalism takes a somewhat different form. In Québec, like Iceland, the concept of 'blood' has been brought together with the concept of hereditary traits. This has taken place through the fusion of IREP's genealogical database with genetic samples from outside researchers. In other words, information on Québec family lineages has been combined with information on particular genes and hereditary traits of the 'pure laine' Québécois. Another similarity between the forms of genetic nationalism in Québec and Iceland is that both populations are identified through their disease genes, or pathological traits. However, Québec differs from Iceland in that the pathological traits are used to identify only a portion of the Québec population. In Québec, only 'pure laine' Québécois play a biological role in genetic nationalism, since it is only these people who are thought to be descendents of Québec's French founders.

In terms of the researchers at IREP who initiated these studies, the genealogical database and the identification of French founders can be seen as an extension of their political interests. Gérard Bouchard, who led IREP from its founding in 1972 until this year, has a

clear stance on Québec politics – his believes that Québec must separate from the rest of Canada in order to fulfill its potential as a nation. (Bouchard 2000: 51-52 – chapter 3 in Venne 2000) 'Proving' the distinctiveness of true Québécois from outsiders supports his claims that Québécois are different from other Canadians. Their distinctiveness is now shown not only by culture and language, but also by their blood and genes. Gilles Bibeau has suggested that Québec histories have been strategically used to create beliefs about who the Québécois are. (Bibeau 1995) Collective histories have been used to create a heroic past of 'pure laine' Québécois and to promote nationalistic positions. I have already described the selective lines used to trace Québécois, and with whom commonalities were sought (e.g. not Amerindians or English). In the case of Québec, then, I suggest that an imagined homogenous community among 'pure laine' Québécois has been created in order to construct a scientifically 'proven' story of origins. This story can then be used to promote a sense of genetic nationalism, adding to the cultural and political nationalistic sentiments already existing in Québec.

The participation promoted by genetic nationalism in Québec is different than that in Iceland. IREP's project is limited to a genealogical database and does not require fullscale consent of the population as in Iceland. The Québécois' participation in IREP's genealogical research, would be best reflected in the degree of their interest in identifying their 'roots.' In other words, IREP's success in promoting genetic nationalism is reflected in an interest among the Québécois in uncovering information about the founders of their lineage and province. Genealogical studies have been and continue to be an interest of Québécois.

Part IV: Conclusions

Nationalism is a concept that has changed over time, according to shifting social and cultural contexts. In the 16th century, Herder's emphasis on Germany's culture and traditions was consistent with that era's means of identifying populations. The different 'tribes' or nations thought to be descendents of particular biblical figures were distinguished not by their 'race' by primarily through linguistic differences. In the 19th century, advances in the biological sciences made available new concepts of human differences for social theorists. Biological metaphors became the predominant means to justify the social inequalities previously justified by descent ('blood,' as the term was used in a metaphorical sense) and class. These metaphors were also used to distinguish the peoples of each nation from other nations. Economic and social instability in the late 19th century contributed to an escalation of the biological racism that had appeared earlier in the century, reaching its most intense form in Nazi Germany in the early to mid 20th century. After the Second World War, worldwide reactions to the atrocities of the Holocaust and against the Nazis led to a self-conscious removal of biological theories from discussions of human differences. But beginning in the late 20th century, biological metaphors started to return to nationalistic claims, such as in the fracturing of the USSR into smaller nations. Developments in science, including information derived from the human genome project, have started to bring back the concepts of human biological or genetic differences and 'race' back into definitions of nationality. Genetic nationalism may become a more common means of identification as knowledge of personal and collective genetic similarities and differences increases.

The interplay between the biological (or genetic) and the social has been taken up in academic discourses. Interest in this area of study has been increasing since the early 1980s, exemplified by the growth of the field of social studies of science. Anthropologists working within this field examine the social embeddedness of scientific knowledge and practices. This can involve investigations of tools (either physical or conceptual), scientific categories, belief systems underlying methods of treatment, etc. Anthropologists in the social studies of science examine the influence of society and culture on scientific practices and also how science loops back, affecting the society within which it exists.

Specific examples of research within the social studies of science include researchers who trace the histories and historical contexts of certain scientific fields (e.g. psychiatry, pharmaceuticals). These studies attempt to understand the complexity of forces within the scientific field they are studying, and investigate how and why the products (e.g. drugs, tools, diagnoses) and knowledge were produced. These studies also examine how the products and knowledge influence the societies in which they are used. (Hacking 1998; Healy 1997; Young 1995) Other anthropologists start with a diagnosis or technology and examine the assumptions embedded within its creation and the social implications of its use. (Lock 1993; Rapp 1999) Others still focus on questions of ethics and change within science, whether laying claim to an ethical stance or not, in addition to examining the role of powerful leaders in scientific industries. (Rabinow 1999; Rabinow and Palsson 1999)

The biological and genetic knowledge being produced today is changing the way in which human groups are being conceived. This paper reflects an interest in how the reintegration of these scientific forms of knowledge effect individual and collective identities. It is also an example of the ways in which genetic information is being used by entrepreneurs, nationalists, and interested individuals in order to further their different goals. In the cases of Iceland and Québec, genetic information has been incorporated into the existing means of identifying groups and claims of identity.

References

Abraham, C. 2001. "Private sector wins genetic-code race," in *The Globe and Mail*, pp. A1, A7. Toronto.

Andersen, B., Arnason, Einar. 1999. Iceland's database is ethically questionable. BMJ 318:1565.

Anderson, B. 1983. Imagined Communities: reflections on the origin and spread of nationalism. London: Verso.

Annas, G. J. 2000. Rules for Research on Human Genetic Variation -- Lessons from Iceland. New England Journal of Medicine 342:1830-1833.

Arnason, E., Hlynur Sigurgislason, Eirkur Benedikz. 2000. Genetic homogeneity of Icelanders: fact or fiction? *Nature Genetics* 25:373-374.

Associated_Press. 2001. "Iceland's Adventures in the Gene Trade,", vol. 2001: CNN.

Balitmore, D. 2001. Our Genome Unveiled. Nature 409:814-816.

Berlin, I. 1976. Vico and Herder: Two Studies in the History of Ideas. London: The Hogarth Press.

Bereciartu, G. J. 1994. Decline of the Nation-State. Vol. IV. Ethnonationalism in Comparative Perspective. Reno: University of Nevada Press.

Berrettini, W.H. 2000. Susceptibility Loci for Bipolar Disorder: Overlap with Inherited Vulnerability to Schizophrenia. *Biological Psychiatry* 47:245-251.

Bibeau, G. 1995. Tropismes Québécois: Je me souviens dans l'oubli. Anthropologie et Societes 19:151-198.

Biddiss, M. D. 1970. Father of racist ideology; the social and political thought of Count Gobineau.

Blanckaert, C. 1988. "On the Origins of French Ethnology: William Edwards and the Doctrine of Race," in *Bones, Bodies, Behavior: Essays on Biological Anthropology*, vol. 5, *History of Anthropology*. Edited by G. Stocking. Madison: University of Wisconsin Press.

Bouchard, G. 2000. "Interview," : with Stephanie Lloyd.

Bouchard. 1999. Project BALSAC. Rapport Annuel 1998-1999. IREP (Institut Interuniveristaire de recherches sur les populations) 1998-1999.

Brais, B., Belanger, Liane. 2001. *Rapport biennal 1998-2000*. IREP (Institut interuniversitaire de recherches sur les populations).

Butler, D. 2001. Are you ready for the revolution? Nature 409:758-760.

Cavalli-Sforza, L. L., Feldman, M.W. 1981. Cultural Transmission and Evolution: A Quantitative Approach. Princeton: Princeton University Press.

Cavalli-Sforza, L. L., Paolo Menozzi, and Alberto Piazza. 1994. The History and Geography of Human Genes. Princeton: Princeton University Press.

Chadwick, R. 1999. The Icelandic database – do modern times need modern sagas? *BMJ* 319:441-4.

Chase, A. 1977. The Legacy of Malthus: The Social Costs of the New Scientific Racism. New York: Alfred A. Knopf.

Coghlan, A. 1998. Selling the family secrets. New Scientist :20-21.

Collins, F. S., McKusick, Victor A. 2001. Implications of the human genome project for medical science. *JAMA* 285:540-544.

Craddock, N., Jones, Ian. 1999. Genetics of Bipolar Disorder. Journal of Medical Genetics 36:585-594.

Crow, J. F. 2001. The beanbag lives on. Nature 409:771.

Dagur. 2000. "Man of the week fell out of the closet!," in Dagur. Reykjavik.

De Braekeleer, M. 1991. Hereditary Disorders in Saguenay-Lac-St-Jean. Human Heredity 41:141-146.

De Braekeleer, M., Dao, To-Nga. 1994. Hereditary Disorders in the French Canadian Population of Quebec. II. Contribution of Perche. *Human Biology* 66:225-249.

DV. 2000. "The Vice Director General of Public Health opted out of deCODE's database," in *DV*. Reykjavik.

Edwards, J. H. 1999. Unifactorial models are not appropriate for multifactorial disease. *BMJ* 318:1353.

Evans, K. L., Muir, Walter J., Blackwood, Douglas H.R., Porteous, David J. 2001. Nuts and bolts of psychiatric genetics: building on the Human Genome Project. *Trends in Genetics* 17:35-40.

Finzsch, N., Schirmer, Dietmar. Editor. 1998. Identity and Intolerance: Nationalism, Racism, and Xenophobia in Germany and the United States. Vol. 19. Publications of the German Historical Institute, Washington, D.C. Cambridge: Cambridge University Press (and German Historical Institute, Washington, D.C.). Friddle, C., Rebecca Koskela, Koustubh Ranade, Joan Hebert, Michele Cargil, Chris D. Clark, Melvin McInnis, Sylvia Simpson, Francis McMahon, O. Colin Stine, Deborah Meyers, Jianfeng Xu, Dean MacKinnon, Theresa Swift-Scanlan, Kay Jamison, Susan Folstein, Mark Daly, Leo. 2000. Full-Genome Scan for Linage in 50 Families Segregating the Bipolar Affective Disease Phenotype. *American Journal of Human Genetics* 66:205-215.

Gellner, E. 1983. Nations and Nationalism. Ithaca: Cornell University Press.

Gershon, E. S. 2000. Bipolar Illness and Schizophrenia as Oligogenic Diseases: Implications for the Future. *Biological Psychiatry* 47:240-244.

Gilman, S. 1991. The Jew's Body. New York: Routledge.

Gradie, M. I., Lynn B. Jorde, and Gérard Bouchard. 1988. Genetic Structure of the Saguenay, 1852-1911: Evidence from Migration and Isonymy Matrices. *American Journal of Physical Anthropology* 77:321-333.

Greely, H. T. 1998. Legal, Ethical, and Social Issues in Human Genome Research. Annual Review of Anthropology 27:473-502.

Greely, H. T. 2000. Iceland's Plan for Genomic Research: Facts and Implications. *Jurimetrics* 40:153-191.

Greely, H. T. 2000. Iceland's Plan for Genomic Research: Facts and Implications. *Jurimetrics* 40:153-191.

Greenwood, J. 2000. "The business of genes. Newfoundland a motherlode for geneticists.," in *Financial Post (National Post)*, pp. D1, D5. Toronto.

Gulcher, J., Stefansson, Kari. 1999. "The Icelandic Healthcare Database: A tool to create knowledge, a social debate and a bioethical and privacy challenge,", vol. 2000: Medscape, Molecular Medicine Journal.

Gulcher, J., A. Helgason and K. Stefansson. 2000. Genetic homogeneity of Icelanders. *Nature Genetics* 26:395.

Hacking, I. 1998. Mad Travelers: Reflections on the Reality of Transient Mental Illnesses. Charlottesville: University of Virginia Press.

Haeckel, E. 1898. *The Evolution of Man: a popular exposition*, 3rd edition. Vol. I. New York: D. Appleton and Company.

Harrison, F. V. 1995. The Persistent Power of "Race" in the Cultural and Political Economy of Racism. *Annual Review of Anthropology* 24:47-74.

Healy, D. 1997. The Antidepressant Era. Cambridge: Harvard University Press.

Henderson, M. 2001. "Front page," in The Times, pp. 1, 5, 10. London.

Herring, R. 2000. "The Doctor is Kin,", 18 May 2000 edition, vol. 2000: Red Herring online magazine.

Herrnstein, R. J., Murray, Charles. 1994. The Bell Curve: Intelligence and Class Structures in American Life. New York: Free Press.

Heyer, E. 1995. Genetic Consequences of Differential Demographic Behaviour in the Saguenay Region, Québec. American Journal of Physical Anthropology 98:1-11.

Heyer, E. 1995. Mitochondrial and Nuclear Genetic Contribution of Female Founders to a Contemporary Population of Northeast Québec. *American Journal of Human Genetics* 56:1450-1455.

Heyer, E. 1999. One Founder / One Gene Hypothesis in a New Expanding Population: Saguenay (Québec, Canada). *Human Biology* 71:99-109.

Heyer, E., Marc Tremblay, and Bertrand Desjardins. 1997. Seventeenth-Century European Origins of Hereditary Diseases in the Saguenay Population (Québec, Canada). Human Biology 69:209-225.

Hobsbawm, E., Ranger, Terence. 1983. *The Invention of Tradition*. London: Cambridge University Press.

Hutchinson, J. 1992. "Moral Innovators and the Politics of Regeneration: the Distinctive Role of Cultural Nationalists in Nation Building," in *Ethnicity and Nationalism*, vol. 55, *International Studies in Sociology and Social Anthropology*. Edited by A. D. Smith. Leiden: E.J. Brill.

Ikonomov, O. C., Husseini, Manji K. 1999. Molecular Mechanisms Underlying Mood Stabilization in Manic-Depressive Illness: The Phenotype Challenge. *American Journal of Psychiatry* 156:1506-1514.

James, P. 1996. Nation Formation: Towards a Theory of Abstract Community. Politics and Culture: A Theory, Culture and Society Series. London: Sage Publications.

Jimenez-Sanchez, G., Barton Childs, David Valle. 2001. Human Disease Genes. *Nature* 409:853-855.

Jonatansson, H. 2000. Iceland's Health Sector Database: A Significant Head Start in the Search for the Biological Grail or an Irreversible Error? *American Journal of Law and Medicine* 26:31-67.

Kanigel, R. 2001. "The Seven Daughters of Eve': Xenia, Paleolithic Princess," in New York Times. New York.

Kirov, G., M. Rees, I. Jones, F. MacCandless, M. J. Owen, and M. Craddock. 1999. Bipolar disorder and hte serotonin transporter gene: a family-based association study. *Psychological Medicine* 29:1249-1254.

Kong, A. 1999. Does Genealogy Matter for Complex (Multifactorial) Genetic Disease? BMJ 318:1353.

Kong, A., Gulcher, Jeff, Stefansson, Kari. 1999. Genealogy certainly matters for multifactorial genetic disorders. *BMJ* 319:578.

Lifton, R. J. 1986. The Nazi Doctors: Medical Killing and the Psychology of Genocide. United States: Basic Books (a division of Harper Collins).

Lock, M. 1993. Encounters with Aging: Mythologies of Menopause in Japan and North America. Berkeley: University of California Press.

Manji, H. K., Joseph M. Bebchuk, Gregory J. Moore, Debra Glitz, Khondakar A. Hasanat, Guang Chen. 1999. Modulation of CNS Signal Transduction Pathways and Gene Expression by Mood-Stabilizing Agents: Therapeutic Implications. *Journal of Clinical Psychiatry* 60:27-39.

Mannvernd. 2000. "Mannvernd website," www.mannvernd.is, vol. 2000: Mannvernd (the Association of Icelanders for Ethics in Science and Medicine).

Marshall, E. 1998. Iceland's blond ambition: a Nordic country cashes in on its isolated gene pool. *Mother Jones*.

Mauron, A. 2001. Is the Genome the Secular Equivalent of the Soul? Science 291:831-2.

McGuffin, P., Brien Riley and Robert Plomin. 2001. Toward Behavioral Genomics. *Science* 291:1232-1249.

McInnis, M. G. 1999. The assent of a nation: genethics and Iceland. *Clinical Genetics* 55:234-239.

Morissette, J., A. Villeneuve, L. Bordeleau, D. Rochette, C. Laberge, B. Gagne, C. Laprise, G. Bouchard, M. Plante, L Gobeil, E. Shink, J. Weissenbach, and N. Barden. 1999. Genome-Wide Search for Linage of Bipolar Affective Disorders ina Very Large Pedigree Derived From a Homogeneous Population in Québec Points to a Locus of Major Effect on Chromosome 12q23-q24. *American Journal of Medical Genetics* (Neuropsychiatric Genetics) 88:567-587.

Nadeau, J. H. R. B., Greg Barsh, David Beier, S.D.M. Brown, Maja Bucan, Sally Camper, George Carlson, Neal Copeland, Janan Eppig, Colin Fletcher, Wayne N. Frankel, Detlev Ganten, Dan Goldowitz, Chris Goodnow, Jean-Louis Guenet, Geoff Hicks, Martin Hrabe de Angelis, Ian Jackso. 2001. Sequence Intrepretation: Functional Annotation of Mouse Genome. *Science* 291:1251-1255.



Nairn, T. 1997. Faces of Nationalism: Janus Revisited. London: Verso.

Paabo, S. 2001. Genomics and Society: The human genome and our view of ourselves. *Science* 291:1219-1220.

Palsson, G., Rabinow, Paul. 1999. Iceland: the case of a national genome project. *Anthropology Today* 15:5.

Pennisi, E. 2001. The Human Genome. Science 291:1177-1180.

Pick, D. 1989. Faces of Degeneration: a European Disorder, 1848-1918. Cambridge: Cambridge University Press.

Poliakov, L. 1975. *The History of Anti-Semitism*. Vol. Three: From Voltaire to Wagner. New York: Vanguard Press.

Poliakov, L. 1985. The History of Anti-Semitism. Vol. IV. Suicidal Europe, 1870 - 1933 (The Littman Library of Jewish Civilization. Oxford: Oxford University Press.

Pollack, A. 2001. "Business Section," in New York Times, pp. C1, C4. New York.

Proctor, R. 1988. "From Anthropologie to Rassenkunde in the German Anthropological Tradition," in Bones, Bodies, Behavior: Essays on Biological Anthropology, vol. 5, History of Anthropology. Edited by G. Stocking. Madison: University of Wisconsin Press.

Provine, W. B. 1971. The Origins of Theoretical Population Genetics. Chicago: University of Chicago Press.

Rabinow, P. 1999. French DNA: Trouble in Purgatory. Chicago: University of Chicago Press.

Rapp, R. 1999. Testing Women, Testing the Fetus: the social impact of amniocentesis in America. The Anthropology of Everyday Life. New York: Routledge.

Serretti, A., Roberta Lilli, Cristina Lorenzi, Enrico Smeraldi. 1999. No association between serotinin-2A receptor gene polymorphism and psychotic symptomatology of mood disorders. *Psychiatry Research* 86:203-209.

Service, R. F. 2001. Can data banks tally profits? Science 291:1203.

Sher, L. 2001. Candidate gene studies in psychiatric disorders: promises and limitations. *Journal of Psychiatry and Neuroscience* 26:103-5.

Smith, A. D. Editor. 1992. Ethnicity and Nationalism. Vol. 55. International Studies in Sociology and Social Anthropology. Leiden: E.J. Brill.

Sommerville, A., English, Veronica. 1999. Genetic privacy: orthodoxy or oxymoron? *Journal of Medical Ethics* 25:144-150.

Specter, M. 1999. Decoding Iceland. New Yorker :40-51.

Stahl, S. M. 2000. New Drug Discovery in the Postgenomic Era: From Genomics to Proteomics. *Journal of Clinical Psychiatry* 61:894-5.

Stefansson, K. 1998. "Hunting Genes in Iceland,", vol. 1999: Elsevier Science.

Stocking, G. W. 1968. Race, Culture, and Evolution: Essays in the History of Anthropology. New York: The Free Press.

Stocking, G. W. Editor. 1988. Bones, Bodies, Behavior: Essays on Biological Anthropology. Vol. V. History of Anthropology. Madison: University of Wisconsin Press.

Stoneking, M. 2001. From the evolutionary past... Nature 409:821-822.

Trivedi, B. P. 2000. "Icelanders, a diverse bunch?,", 11August 2000 edition, vol. 2000: Celera Science Articles.

Venne, M. Editor. 2000. Penser la nation Québécoise. Montreal: Editions Québec Amerique.

Vezina, H., Evelyne Heyer, Isabel Fortier, Gail Ouellette, Yves Robitaille, and Denis Gauvreau. 1999. A genealogical study of Alzheimer Disease in the Saguenay Region of Québec. *Genetic Epidemiology* 16:412-425.

Vezina, H., L. Houde, H. Charbonneau, M. Beaudry, A. Cholette, N. Daoud, J. Mathieu, Y. Robitaille, F. Veilleux, and D. Gauvreau. 1996. Season of birth and Alzheimer's disease: a population-based study in Saguenay-Lac-St-Jean / Québec (IMAGE Project). *Psychological Medicine* 26:143-149.

Vincent, J. B., Mario Masellis, Jacob Lawrence, Victor Choi, Hugh Gurling, Sagar V. Parikh, and James L. Kennedy. 1999. Genetic Association Analysis of Serotonin System Genes in Bipolar Affective Disorder. *American Journal of Psychiatry* 156:136-138.

Wade, N. 2001. "Genome Mappers Navigate the Tricky Terrain of Race," in New York Times. New York.

Weingart, P. 1998. "The Thin Line Between Eugenics and Preventive Medicine," in *Identity and Intolerance: Nationalism, Racism, and Xenophobia in Germany and the United States*, vol. 19. Edited by N. Finzch, Schirmer, Dietmar. Cambridge: Cambridge University Press (and German Historical Institute, Washington, D.C.).

Williamson, R. 1999. What's 'new' about 'genetics'? Journal of Medial Ethics 25:75-76.

Woolfson, A. 2001. "So much for genes. A review of *The Century of the Gene* by Evelyn Fox Keller.," in *London Review of Books*, vol. 23.



Young, A. 1995. *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder*. Princeton: Princeton University Press.

-