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Howard Markel, M.D., PhD.

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I. INTRODUCTION

HISTORIANS ARE BY NATURE HESITANT to predict the future. Consequently, I approach this discussion of the BRCA1 gene's association with the Ashkenazi-Jewish population, based upon a consideration of previous associations of this population and eugenics, with some trepidation. But while history does not repeat itself exactly "in alternating currents" of thirty year cycles as Arthur M. Schlesinger, Jr. once suggested, there are recurrent themes that may be revealed by the historical study of this topic. Indeed, many historians would agree that past interactions of this population with genetic issues have the potential to be culturally and socially embedded in contemporary responses to the relatively high association of the BRCA1 gene among Ashkenazi-Jewish women. There are also areas of stark contrast between eugenic theories of the early twentieth century and contemporary biological debates that should help to further elucidate our collective study of the
social implications of genetic technologies. For example, pathbreaking work by such scholars as Daniel J. Kevles, Kenneth M. Ludmerer, Troy Duster, Diane B. Paul, and Garland E. Allen show how several episodes in recent American history involving the application of genetic or eugenic theories to social policies have been framed by issues of race, ethnicity, socioeconomic status, and gender. One example of the complex mix of race, thought, ethnicity, and eugenic theory was the move to restrict immigration for specific social groups in the United States during the 1920s. One of the largest, but certainly not the only, eugenically stigmatized, ethnic groups of this period were East European or Ashkenazi Jews. As such, I would like to discuss the following: 1) the history and migration patterns of the Ashkenazi or East European Jews; 2) the East European Jewish immigrant’s experience with the eugenics movement in the United States during the first three decades of the twentieth century; and, 3) some of the ethical, social, legal, and ethnic implications of the recent discovery of BRCA1.

A. Definition of the Ashkenazi Population

Ashkenazi Jews comprise about eighty-two percent of all Jews in the world. The name, Ashkenazi, originates from the Hebrew word for Germany, where many of the original Ashkenazim first settled. This term more broadly represents all of the Jewish communities of Western and Eastern Europe. Initially, the migration of Jews during the tenth and eleventh centuries proceeded from Spain to Western Europe. After the Crusades of the eleventh century, Jews fled France, Germany,
and England and went to Eastern Europe; specifically, Poland, Lithuania, Volhynia, and Russia. It is for this reason that many historians alternatively characterize this group as East European Jews. The Jews living in these areas most commonly engaged in small businesses such as inn keeping, dealing in furs, textiles and lumber, vodka manufacturing, and similar mercantile activities. Their lives were also enriched by a unique and now lost culture of East European Jewry, affectionately referred to as *Yiddishkeit*. By the close of the sixteenth century, Eastern Europe was the major center of the Jewish world.\(^3\)

Although in many ways East European Jewry flourished during the sixteenth and seventeenth centuries, there were already signs of hostility and anti-Semitism among their neighbors. The enactment of anti-Semitic edicts and occasional physical brutality against Jews during this period elevated tensions and only made matters worse. This oppressive atmosphere, unfortunately, was but a mere prologue to the plight of East European Jewry during the nineteenth and first half of the twentieth centuries.\(^4\)

**B. The Pale of Settlement**

In 1772, Poland was partitioned between Russia, Prussia, and Austria. Those sections that comprised the largest Jewish settlement areas, eastern Poland, Lithuania, Byelorussia, Podolia, and the Ukraine were incorporated into the Russian empire.

The “Jewish question” aroused great concern in the Czarist courts of the nineteenth century. For example, in 1803 Czar

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Nicholas I exiled an overwhelming majority of Russian Jewry to the Pale of Settlement, an area that was comprised of fifteen western districts of Russia and ten districts of the former kingdom of Poland. Nicholas' heir, Alexander II, attempted to remove some of the harsher sanctions against this population during his reign (1855-1881). However, this respite came to a crashing halt with the accession of Alexander III after his father's assassination at the hands of anti-Czarist terrorists.

Czar Alexander III pursued a steady anti-Jewish policy during his twelve-year reign beginning with the infamous 1882 May Edicts that limited Jews from traveling across the Empire and also limited their business dealings and religious rituals. Furthermore, these laws barred Jews from entering Russian universities and enforced conscription into the Russian Army for all-first born Jewish males between the ages of twelve and eighteen. But most trying of all for the Russian Jews were the mass orders of expulsion and the violent pograms that threatened their lives. At the arbitrary whim of a provincial governor, an entire shtetl, or village population, could be abruptly ordered to resettle or leave the Pale entirely. Worse still, Jews of the Pale were commonly beaten, killed, or spat upon. Moreover, their cemeteries and synagogues were vandalized, and they were exposed to other atrocities without any means of recourse or protection. The Russian partitioning of the Jews was so successful that by 1897, approximately 4,900,000 Jews, or ninety-four percent of the entire Russian Jewish population, lived in the 386,000 square mile Pale from the Baltic to the Black Sea. As the social critic and historian Irving Howe observed: "[n]either stability nor peace, well-being nor equality, was possible for the Jews of Russia."

C. The World of the Shtetl

One of the most striking social features of East European Jewry during this period was its isolation from the Gentile

5. See Irving Howe, World of Our Fathers 7 (1976). Cf. I. Michael Aronson, Troubled Waters: The Origins of the 1881 Anti-Jewish Pogroms in Russia (1990) (describing the anti-Jewish sentiment that flowed through Russia, but arguing that the widely held assumption that the Russian government supported pogroms may be false).
Russian and Polish cultures. Jews tended to live in small towns or villages, called shtetls, throughout the districts of the Pale where their own Jewish culture flourished. East European Jews, too, were active participants in this process of social separation. Most East European Jews believed in long-held traditions that called for a complete separation from the secular or Gentile world. Their deeply held religious and cultural convictions and a language, Yiddish, that was markedly different from their Russian or Polish neighbors, only fortified the social walls of the economic, geographical, and legal sanctions built around them. I have written elsewhere that it would be difficult to find a better social metaphor for isolation than the Jews of the Pale of Settlement. Indeed, it is this remarkable four century localization of one population, Ashkenazi Jews, to one area, the Pale, that makes them so interesting from a genetic epidemiological point of view.

D. Migration of East European Jews

Given the harsh living and social conditions of the Pale of Settlement, Jews began emigrating out of Eastern Europe in massive numbers, mostly to the United States (ninety-five percent of all Jewish immigration to the United States took

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6. See generally Mark Zborowski & Elizabeth Herzog, Life Is With People: The Jewish Little-Town of Eastern Europe (1952). This is not to say that the East European Jews had no contact with their Gentile neighbors. The marketplace and mercantile exchange was but one place these cultures interacted on a daily basis. For a discussion of the intercourse between East European Jews and Russian peasants living in the Pale during the late 19th century refer to Tracing An-Sky, supra note 3, at 16-56. See also Irving Howe, World of Our Fathers 417-56 (1989) (discussing the Yiddish language and Yiddishkeit (Yiddish culture)).

7. See Howard Markel, Quarantine! East European Jewish Immigrants and the New York City Epidemics of 1892 (forthcoming Spring 1997).

8. See Neil Risch et al., Genetic Analysis of Idiopathic Torsion Dystonia in Ashkenazi Jews and Their Recent Descent from a Small Founder Population, 9 Nature Genetics 152, 152 (1995). Some geneticists have hypothesized that the association of rare disorders such as Tay-Sachs and Primary Torsion Dystonia with Ashkenazim is due to the rapid growth of a population that emerged from a small group of founders (founder's effect) and genetic drift. Id. at 152. Other geneticists have argued that rare genetic conditions such as Tay-Sachs may be the result of heterozygote advantage. See, e.g., L.B. Jorde, Genetic Diseases in the Ashkenazi Population: Evolutionary Considerations, in Genetic Diversity Among Jews: Diseases and Markers at the DNA Level 305, 305-18 (Batsheva Bonné-Tamir & Avinoam Adam eds., 1992); Richard M. Goodman, A Perspective on Genetic Diseases Among the Jewish People, in Genetic Diseases Among Ashkenazi Jews, supra note 4, at 1-17 (developing a framework that enables a better understanding of the magnitude of genetic diseases among Jewish people and appreciates the need for a multidisciplinary approach to this study).
place during this period), although a small percentage emigrated to Palestine, Argentina, South Africa, and other locations. Between 1880 and 1924, more than 2,100,000 Jews immigrated to the United States, a number that comprised about thirty-three percent of all the Jews living then in Eastern Europe. Subsequent events in world history, particularly the infamous Nazi Holocaust of World War II, led to further migrations of Ashkenazi Jews, although in much smaller numbers, out of Eastern Europe. The recent fall of Communism and the changes in the Soviet Union have inspired still another mass migration of East European Jews, mostly to Israel and the United States. As of 1991, demographic estimates of the world's Jewish population are about 12,810,000, with the majority living in the United States, Canada, and Israel.

One significant change that occurred in this population with the passage of time and the massive human migrations is the loss of insularity, both social as well as genetic, that was once observed in those Ashkenazi-Jewish populations living in the Pale of Settlement between the fifteenth and late nineteenth centuries. As migration out of Eastern Europe continued, distinct cultural and social changes began to emerge that make retrospective genetic epidemiological studies extending into the twentieth century problematic and somewhat difficult to interpret. In the United States during the early twentieth century, for example, there existed a number of social and cultural restrictions among the different Jewish-American communities that may have kept a newly-arrived Russian Jew from marrying, say, a more patrician and established Sephardic Jew. Examples of the almost hierarchical social spheres within the American-Jewish community of this era can be seen in the different social institutions maintained by different Jewish groups in the United States; synagogues, neighborhoods, benevolent organizations, and social clubs were frequently bound along lines of class and geographic origins. These class distinctions and the continued separation of Ashkenazi Jews from other Jews and Gentiles gradually eroded over the first half of the twentieth century. Over the past twenty-five years, this process has only accelerated and American Jews have assimilated more and more into mainstream American society. Currently, old concerns over where one’s “people” came from or
the acceptability of East European Jews to a German Jewish or Sephardic Jewish family are rarely, if ever, considered. Moreover, intermarriages among these once separate segments of the Jewish population are quite common. To complicate matters further, intermarriage of Jews and Gentiles has steadily increased over the past century of American life; during the late 1980s and early 1990s, about one out of every three American Jews married out of the Jewish faith. Such changes in the actual genetic admixture of different Jewish and Gentile populations, markedly changing concepts of race over the past 150 years, and even the social transmutability of how individuals define their origins or "roots" all need to be carefully considered before labeling an observed mutation as an "Ashkenazi Jewish disease." One valuable lesson we can glean from the history of genetics is to clearly distinguish between the perception of a "disease of ethnicity" and a disease which has an association with some members of an ethnic group.

II. EUGENICS AND THE "SCIENTIFIC BASIS" OF IMMIGRATION IN THE UNITED STATES, 1890-1924

One of the best-known applications of hereditary thought to social policy in American history is the collaboration of the Eugenics Record Office (ERO) at Cold Spring Harbor, Long Island with a group of Americans alarmed by the huge rise of immigration from Eastern, Central, and Southern Europe during this period. Prior to the 1880s, the bulk of immigration to the United States (ninety-five percent) originated from countries such as England, Ireland, Scotland, France, Germany, Norway, Sweden, the Netherlands, and Switzerland. By the 1890s, with social unrest, famine, and disease spreading across Eastern, Central, and Southern Europe, there was a huge wave of a "new" type of immigration to American shores, mostly from Russia, Poland, Austria-Hungary, Bulgaria, Greece, Italy,

9. See Stephen J. Whitfield, American Jews: Their Story Continues, in THE AMERICAN JEWISH EXPERIENCE 284, 292 (Jonathan D. Sarna ed., 1986); MAURICE FISHBERG, THE JEWS: A STUDY OF RACE AND ENVIRONMENT 179-224 (1975); Redcliffe N. Salaman, Heredity and the Jew, 3 EUGENICS REV. 187-200 (Apr. 1911 - Jan. 1912). More recent demographic studies of the American Jewish population suggest that this trend is not only continuing, but is rising to about one out of every two unions resulting in intermarriage between American Jews and Gentiles.
Romania, Serbia, Spain, and Turkey. These "new" immigrants were considered by many Americans to be far more troublesome and less assimilable than their "old" counterparts. The late nineteenth century characterization of these new immigrants as "wretched refuse" was not only uttered by the nativist in his parlor, it also appeared in Emma Lazarus's well-known 1883 poem, *The New Colossus* which is inscribed on the Statue of Liberty's pedestal in New York Harbor. This trend only continued as the nineteenth century gave way to the twentieth. Between 1881 and 1920, more than 24,000,000 newcomers made their way to the United States. In 1880, eighty-two percent of foreign-born citizens residing in the United States had emigrated from Northwestern Europe; by 1920, approximately forty-six percent of the immigrants originated from Southern and Eastern Europe.

The term "eugenics" was coined by the British scientist and mathematician, Sir Francis Galton, in 1883. The word was developed from the Greek root for "noble or good in birth" and encompassed Galton's proposals to improve humanity by "giv[ing] to the more suitable races ... a better chance of prevailing speedily over the less suitable." From Galton's humble proposals emerged an entire field of scholarly investigation on heredity around the world during the late nineteenth and early twentieth centuries. In the United States, during an era when scientific approaches to the management of societal ills (the Progressive Era, 1900-1920) was at its height, the "science of eugenics" began to appeal not only to biologists, but also to those desiring its applications to ameliorating social problems such as immigration.
has noted, the eugenics movement "had crucial importance for race-thinking at a time when racial presuppositions were seriously threatened in the intellectual world."\textsuperscript{15} Eugenics offered those in the majority a framework to substantiate their biases against those they considered inferior and dangerous. Those groups judged to be "eugenically superior," such as White Anglo-Saxon Protestants, were encouraged to reproduce. Such encouragement was often referred to as "positive eugenics." Those deemed to harbor "inferior genes," on the other hand, were discouraged from reproducing by "negative eugenics" programs such as the mandatory sterilization laws enacted against the mentally retarded and the restrictive policies directed against incoming, "undesirable" immigrants. In the case of the latter, several prominent eugenicists, such as Lothrop Stoddard, David Starr Jordan, William Z. Ripley, and John R. Commons, warned that the unchecked rise of "undesirable immigration" would weaken and dilute the native American stock with such "inheritable" traits as feeblemindedness, poverty, insanity, and criminal behavior.\textsuperscript{16} Similarly, the founders of the well-known Immigration Restriction League, Prescott F. Hall, Henry Cabot Lodge, Francis Walker, and Robert DeCourcy Ward, in 1912 considered changing the name of their organization to the "Eugenics Immigration League."\textsuperscript{17}

But not all Americans felt comfortable shutting the gates to newcomers given our long history of welcoming the world's oppressed and because of the more pragmatic need for steady, cheap labor in the form of immigrants. Previous calls for immigration restriction based on economic concerns, political or racist fears, and even the threat of epidemic disease were not individually successful in elaborating lasting anti-immigration legislation during the late nineteenth century or the first two decades of the twentieth century. When combined with the racial and eugenic theories of Charles B. Davenport and his

\textsuperscript{15} JOHN HIGHAM, STRANGERS IN THE LAND: PATTERNS OF AMERICAN NATIVISM 1860-1925, at 152 (1963).
\textsuperscript{16} See generally id. at 131-57; LUDMERER, supra note 2, at 87-119.
\textsuperscript{17} See HIGHAM, supra note 14, at 152; BARBARA MILLER SOLOMON, ANCESTORS AND IMMIGRANTS: A CHANGING NEW ENGLAND TRADITION 150 (1956); LUDMERER, supra note 2, at 108.
colleagues at the ERO, however, this cause made far more significant strides towards its restrictionist goals.\textsuperscript{18}

Charles B. Davenport, the director of the Carnegie Institute-Sponsored Station for Experimental Evolution and the ERO, was a Harvard-trained Ph.D. who zealously advanced the generalizations of Gregor Mendel's pea plant observations to humans, and more often, uncritically applied them to his assessment of social problems. As medical historian Charles E. Rosenberg has described Davenport: "[t]here could be no more important social goal, he believed, than the enactment of genetic truths into law."\textsuperscript{19} Indeed, Davenport openly declared war on those groups he perceived as threatening the American "germ plasm" or gene pool with the fervor of a religious crusader. In Davenport's view, the most threatening groups were Russian and Polish Jews and Southern Italians. For example, in 1910, he addressed the American Breeder's Association with a fiery speech asserting that "society must protect itself; as it claims the right to deprive the murderer of his life so also it may annihilate the hideous serpent of the hopelessly vicious protoplasm."\textsuperscript{20} Perhaps more candidly, in a letter to Madison Grant, the best-selling author of the anti-Semitic, eugenics "treatise" \textit{The Passing of the Great Race},\textsuperscript{21} Charles Davenport lamented: "[o]ur ancestors drove Baptists from Massachusetts Bay into Rhode Island but we have no place to drive the Jews to. Also they burned the witches but it seems to be against the mores to burn any considerable part of our population."\textsuperscript{22}

Unfortunately, Davenport and the scores of biologists, social workers, and field workers he attracted to Cold Spring Harbor were not entirely successful in critically advancing the study of the laws of heredity. The methods and approaches to


\textsuperscript{19} ROSENBERG, supra note 14, at 91 (discussing Charles Benedict Davenport and his contributions to the eugenics movement).


\textsuperscript{22} Letter from Charles B. Davenport to Madison Grant (April 7, 1925) (Charles B. Davenport Papers, on file with American Philosophical Society) \textit{quoted in ROSENBERG, supra note 14}, at 95-96 (lamenting that the only hope for the republic lay in the restriction of immigration).
the studies of the ERO have been analyzed elsewhere by Garland Allen and Daniel Kevles, but it should be noted that many of these studies were faulty compendiums of pedigree analyses and case studies based almost exclusively upon subjective impressionistic data. From the reams of paper compiling these studies, Davenport and his associates explained the hereditary basis of lust, avarice, and criminal behavior in various ethnic groups, thallosophilia (a love of the sea) among naval families, and nomadism among gypsies, railroad workers, and hoboes. Davenport attributed all of these traits, incidentally, to single Mendelian genes.23

The social impact of the ERO, however, was far broader than its original mission of serving as a research center on human heredity and as a clearinghouse for educating the public on eugenics. Their studies that "proved" the genetic inferiority of East European Jews, Southern Italians, Balkans, Greeks, and other "new immigrants" found great resonance among those espousing immigration restriction for more traditional reasons. As Daniel Kevles has noted, Davenport was originally hesitant to employ ERO data for legal or legislative purposes, but his "objection to governmental involvement was selective."24 Indeed, Davenport supported and encouraged the work of his "right-hand man," Harry H. Laughlin, the superintendent of the ERO, to play an increasingly influential role in the development of national policies governing immigration. Laughlin, who shared most, if not all, of Davenport's social prejudices, emerged in the 1920s as the U.S. House of Representatives Committee on Immigration and Naturalization's "expert witness" on eugenics. Invited by Congressman Albert Johnson of Washington State, Laughlin was extremely influential in the passage of the Immigration Restriction Act of 1924, a law that essentially reduced the massive wave of "new immigration" to a mere trickle.

In a series of well-publicized hearings and reports, armed with intricate pedigree charts, graphs, and tables, Laughlin in-

24. KEVLES, supra note 2, at 102 (discussing Charles Davenport's support of Harry Laughlin who was an advocate of views that accorded with Davenport's own social prejudices).
sisted on the "irrefutable truth" of the genetic inferiority of the "new immigrants." Not all of Laughlin's charts, however, substantiated these claims. For example, in a survey of insane asylum inpatients across the United States, Laughlin documented far more native-born Americans than foreign-born committed to psychiatric asylums. Laughlin explained away these findings by stating that the social situation they described was only temporary. He asserted that with the deleterious recessive genes that were imported into the nation by Eastern, Central, and Southern European immigrants. It was only a matter of time before these "biologically inferior" immigrants would reproduce, multiply, and permanently damage the American "germ plasm," not to mention fill up the insane asylums. Historian Garland Allen described the dangerous use of poorly constructed science in guiding social policy by documenting Laughlin's success in giving the United States Congress a "scientific rationalization" for passing an extremely specific and punitive immigration law: "[t]he groups who were most restricted (Jews, Mediterraneans, particularly Italians, and people from Central Europe) were also the ones Laughlin claimed were the most biologically inferior." To be sure, the threat of "bad genes" was not the only or even the overriding rationale behind the push to restrict immigration during the 1920s. In a period of American history when science was heralded and perceived by the public as a panacea for all of society's problems, the blending of biology and racism did, however, prove to be a powerful rationalization for long-held ideas of anti-immigrant sentiment.

III. THE STIGMA OF EUGENICS: THE AMERICAN-JEWISH PERSPECTIVE

Even the most carefully thought-out and administered

26. Id.
27. Id.
28. See Allen, supra note 2, at 175-81 (discussing Charles B. Davenport's commitment to the Mendelian theory of heredity).
policy of disease separation can be deleterious, if you happen to fit the criteria for exclusion or isolation. Those most stigmatized by the Immigration Restriction Act of 1924, particularly East European Jews, Southern Italians, and Central Europeans were not silent in the eugenics debate even though their opinions were rarely heeded. For example, some American Jews offered intellectual counter-arguments phrased in the language of eugenics. In 1911, New York City physician, Dr. Maurice Fishberg published a 578 page treatise entitled The Jews: A Study of Race and Environment. This anthropological study rejected the "pseudo-scientific veneer" of eugenic assertions that the "Jewish race" was inferior and "entirely alien in Europe." Conversely, in 1916, biblical scholar Max Reichler attempted to point out the superior eugenic qualities of the Jewish people based upon a study of the Old Testament:

Why did the Jews survive the onslaught of Time, when others, numerically and politically stronger, succumbed? Obedience to the Law of Life, declares the modern student of eugenics, is the saving quality which rendered the Jewish race immune from disease and destruction.

More commonly, as documented in the American Yiddish press, proceedings of various East European Jewish social agencies and organizations, government hearings, and similar sources, we find ample evidence that the East European Jewish, and more broadly, the entire Jewish-American communities, were deeply offended and worried about the intimidating claims of their eugenic inferiority. In rebuttal to the many books and reports that identified Jews as a risk to the American gene pool, a number of prominent Jewish Americans made their way to Capitol Hill during the early 1920s to register their protest. Among those who protested were Rabbi Stephen Wise, civil rights attorney Louis Marshall, John Bernstein, President of the Hebrew Immigration Aid Society, Joshua Kantrowitz of the Independent Order of B'nai B'rith, and a number of editors and journalists from the American Yiddish

29. See Markel, supra note 7.
30. See Fishberg, supra note 9, at 516.
immigrant press in New York City. For example, in early 1924, William Eldin, the editor of the New York Jewish Day (Der Tog), urged the immigration committee not to base their legislation solely on the conclusions of the eugenicists as he plead in a broken yet forceful English: "[L]isten to the patient and not alone to the doctor[!]"  

Perhaps more emphatic during that same day of hearings were the conclusions of Gedalia Bublick, editor of the New York Jewish Daily News:  

Now some gentlemen want to . . . create a new America, with no equality, and they say instead that the man of the Mediterranean race is not born equal to the man of the Nordic race . . . . This new literature [on Eugenics and immigration] . . . will remain a shame to America in her history . . . .

The predominant fear among Jewish-Americans of East European descent during the deliberation of immigration restriction was the biological and legislative "stigma of inferiority." Some interesting historical questions that require further study include how did these communities respond in terms of their health behaviors? After being judged by scientific and medical experts to be "biologically inferior," were East European Jewish immigrants and other stigmatized groups more likely to avoid contact with public health or private physicians? How did this distrust play itself out in other aspects of the individual doctor-patient relationship and, more broadly, community public health initiatives directed at these groups? I hope to share the results of this ongoing historical work with you as the study progresses. Extrapolating from more recent socio-medical studies of immigrant public health, there is considerable data demonstrating the importance of eliminating language and cultural barriers from health care practices. Moreover, it is clear that health care providers must understand various social groups' perceptions of health and disease. Newly arrived

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32. See Restriction of Immigration: Hearings Before the Committee on Immigration and Naturalization, 68th Cong. 360 (1924) (statement of William Edlin, Editor of a foreign language newspaper YIDDISH DAY).
33. Id. at 394 (statement of Gedalia Bublick, Editor, NEW YORK JEWISH DAILY NEWS).
34. Id.
35. See generally Meryl Brod & Suzanne Heurtin-Roberts, Cross-Cultural Medicine, A Decade Later: Older Russian Emigres and Medical Care, 157 W. J. MED. 333, 333-36 (1992) (explaining the influences of culture on aging Russian emigres' health as well as their interaction with the American medical system). See also Mary Davies & May Yoshida, A Model for Cultural
immigrants, whether they are East European Jews of the early twentieth century or Mexican refugees of our current era, to name but two, are vulnerable social groups for many levels of stigmatization. Biological pronouncements of such a social group's "inferiority" only heighten this vulnerability and may have significant health implications.

IV. CONCLUSION: ONE HISTORIAN'S MUSINGS ON THE "FUTURE" OF THE BRCA1 GENE

The history of eugenic theory and its relationship to U.S. immigration policy provides an interesting historical footnote to the discussion of the social implications of inherited breast cancer in Jewish women, but it is a less germane comparison than, perhaps, the recent experiences with Tay-Sachs screening programs among a more assimilated and confident American-Jewish community of the 1970s. I view this historical analysis of eugenics less as an oracle of what may come to pass, but rather as an opportunity to look at one example where hereditary thought was used inappropriately to substantiate racist beliefs and, therefore, social stigmatization resulted.

There are many other reasons to be optimistic about the minimization of stigma to the Ashkenazi-Jewish community based upon issues of ethnicity alone beyond this confidence of assimilation. Unlike a more classic Mendelian pattern of hereditary disease, such as the recessive genes for Tay-Sachs Disease and Sickle Cell Disease, the discovery of the 185delAG mutation on exon 2 of the BRCA1 gene does not absolutely confirm that the patient will (or will not) develop breast cancer. Further, breast cancer remains relatively common among all American women rather than one ethnic group. These factors should, hopefully, help to fortify arguments against those who perceive breast cancer to be a "Jewish disease" as diabetes mellitus was once considered in the early twentieth century. But it remains incumbent upon those of us involved in the development and implementation of genetic technologies to be aware of the potentially synergized stigma that can result when

Assessment of the New Immigrant, CAN. NURSE, Mar. 1981, at 22-23 (describing the importance of understanding culture as it translates into treating foreign-born patients).
a so-called "undesirable" social group is identified as being the source of a particular disease.

Instead, I worry more about the deeper problems associated with the discovery of the BRCA1 gene and the recent attempts to mass-market breast cancer genetic screens. Indeed, one might argue that the ethical dilemma recently generated are unique products of late twentieth century America. For example, an advertisement on the World Wide Web by the Genetics and In-Vitro Fertilization Institute of Fairfax, Virginia offers such tests for breast and ovarian cancer. The Institute’s director, Dr. Joseph D. Schulman, has justified this marketing based on the “woman’s right to know.” Unfortunately, how these results will be interpreted, how the patients will be counseled, and how this information will be protected in a confidential manner from the view of potential employers or insurers has not been as clearly worked out. More telling is the fact that neither clinicians nor patients know exactly what to do with the results, or how such information will affect breast cancer treatment and management. In some cases, knowing what is or is not “brewing” inside of your body may cause harm rather than good. Ethnicity and social vulnerability, then, are just a few of the myriad considerations we need to incorporate into the planning of genetic screening programs for the twenty-first century that both promote public health and protect the individual from new forms of genetic stigmatization.