

# The Human Genome Project and Eugenic Concerns

Kenneth L. Garver,<sup>\*,†</sup> and Bettylee Garver<sup>\*</sup>

<sup>\*</sup>Department of Medical Genetics, Western Pennsylvania Hospital, and <sup>†</sup>University of Pittsburgh, Graduate School of Public Health and School of Medicine, Pittsburgh



## Summary

The U.S. Human Genome project is the largest scientific project funded by the federal government since the Apollo Moon Project. The overall effect from this project should be of great benefit to humankind because it will provide a better understanding both of single gene defects and multifactorial or familial diseases such as diabetes, arteriosclerosis, and cancer. At first this will lead to more exact ways of screening and diagnosing genetic disease, and later it will lead, in many if not most instances, to specific genetic cures. However, in the past, in both the U.S. and German eugenic movements genetic information has been misused. Hopefully, by remembering and understanding the past injustices and inhumanity of negative eugenics, further misuse of scientific information can be avoided.

## Introduction

The Human Genome Project is a worldwide effort that includes scientists from the United States, Canada, Great Britain, Europe, Russia, and Japan, who are developing new skills and technologies in order to map and sequence all of the estimated 3 billion bp that make up the human genome. This project will yield information on the entire DNA contained in a human being, not only of the protein coding genes (exons) but also the genetic material between these genes (introns) whose function, until now, has been relatively unknown. The cost of this project was estimated to be \$3 billion but could possibly exceed this amount (Dulbecco 1986; De Lisi 1988; Short 1988; Dickson 1989*a*, 1989*b*; Sun 1989; Cantor 1990; Watson 1990; Jordan 1992).

The scientific knowledge that will be generated through the research of the Human Genome Project will be exciting and interesting. However, this alone would not justify the expense and energies expended in research. Its primary value to the public will be new information that can be used to successfully diagnose

and eventually treat many of the so-called single gene disorders and, perhaps most important, multifactorial inherited diseases (McKusick 1989; Green and Water-son 1991; Harper 1992). To date, molecular genetics has contributed mostly to our understanding of single gene disorders such as cystic fibrosis, Duchenne muscular dystrophy, myotonic dystrophy, and Huntington disease. Through the Human Genome Project, many more, and eventually most, single gene disorders will have their genes mapped and sequenced, which will be the first step for specific diagnostic tests as well as eventual treatment. Perhaps the greatest contribution of the Human Genome Project, however, will be in understanding and perhaps being able to treat the multifactorial inherited diseases, such as some forms of cancer, coronary artery disease, hypertension, and diabetes mellitus. The overall results of the Human Genome Project will be of tremendous benefit to humankind because they could lead to better understanding and treatment of some of the serious genetically based diseases that are currently present in our society (Lander and Botstein 1986; Scott 1987; Childs and Motulsky 1988; Field 1988; Lubin et al. 1990; Hyer et al. 1991; MacCluer and Kammerer 1991; Bowden et al. 1992; Gutierrez et al. 1992; Wilson 1992).

As with many advances in science and technology, there are concerns not only from the scientists involved but also from the lay public that this information might

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Address for correspondence: Kenneth L. Garver, M.D., Ph.D., Department of Medical Genetics, Western Pennsylvania Hospital, 4800 Friendship Avenue, Pittsburgh, PA 15224.

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be misused (Dickson 1989*a*, 1989*b*; “Eurogenome Programme Suspended” 1989; Aldhous 1991). Therefore, the U.S. Human Genome Project (USHGP) established an Ethical, Legal and Social Implications (ELSI) program so that these anxieties can be addressed and answered while the scientific research is being processed (Vanchieri 1991). The authors of the present paper believe that eugenics should be specifically included in the ELSI program because there is an overlap of ethics, eugenics, legal, and social implications. The past history of eugenic movements in many countries and the potential implications today should be clearly and individually stated.

### *Definition of Eugenics*

The term “eugenics” was first used in 1883 by Francis Galton, who described it as “the study of the agencies under social control that may improve or impair the racial qualities of future generations, either physically or mentally” (Galton 1865, 1901, 1905). A more recent definition would be “the science that deals with all influences that improve the inborn quality of the human race, particularly through the control of hereditary factors” (Garver and Garver 1991, p. 1109; 1992). Eugenics can be divided into negative eugenics, which is a systematic effort to minimize the transmission of genes that are considered deleterious (techniques that have been used in negative eugenics include involuntary sterilization, involuntary euthanasia, and genetic discrimination) and positive eugenics, which is a systematic effort to maximize the transmission of genes that are considered desirable. An example would be a sperm bank that accepted samples only from Nobel laureates.

### *A Short History of Eugenics in the United States and Germany*

In the history of eugenics, many common denominators have been present during the past 100 years, when many of the major countries of the world have had an active program in negative eugenics. The two eugenic programs that have been most frequently described are those in Germany and the United States, both of which began during the end of the 19th century and flourished in the first 45 years of the 20th century. The predisposing factors in these two programs were very similar to those in many other countries that will not be discussed because of space limitations.

During the latter part of the 19th century and particularly during the first part of the 20th century there was increasing concern among biologists and social workers in the United States about social issues such as degener-

acy, unemployment, criminality, prostitution, chronic alcoholism, and the increasing number of individuals in mental hospitals (Ludmerer 1969, 1972*a*; Popkin 1974; Murphy 1975; Beckwith 1976; Searle 1976; Haller 1984; Paul 1984; Keveles 1985; Smith 1985). The rediscovery of Mendel’s laws indicated that some human diseases such as feeble-mindedness, congenital defects, epilepsy, and Huntington disease could be inherited in a Mendelian manner (Lindeman and Morgan 1936; Allen 1979, 1984*b*; Sapp 1983). These were all believed by the eugenicist to be genetically related and, hence, controllable by eugenic measures. Concern about possible ways to deal with these problems was heightened after World War I when there was increased unemployment, which was exaggerated by the large number of troops returning from Europe and by increased immigration. This mixture of social and economic problems made eugenic approaches very desirable to many professionals and lay persons. The eugenicists took advantage of these social and economic issues to popularize the concepts of eugenics and to lobby both state and federal governments to enact legislation for eugenics programs.

During the late 19th and early 20th centuries, there were many biologists and other scientists together with social workers, philanthropists, and politicians who were concerned that the population of the United States was moving away from the “Anglo-Saxon superiority” to a lower level because of the increased immigration from southern and eastern Europe (Allan 1936; Dice 1952; Reed 1957; Dunn 1962; Ludmerer 1969; Osborn 1974; Reilly 1983; Marks 1993). The nucleus for the dissemination of the eugenics propaganda was the Eugenics Record Office which was founded at Cold Spring Harbor, Long Island, in 1910, with Dr. Charles Benedict Davenport as director and Dr. Harry Hamilton Laughlin as superintendent (Bird and Allen 1981; Allen 1986). Their efforts were successful, and the Johnson Immigration Restriction Act was passed in 1924 by Congress and signed into law by President Calvin Coolidge. Immigration was based on the quotas established in the 1890 census because this favored immigration of the so-called Nordic or Anglo-Saxon stock, namely people from northwestern Europe and Great Britain, and decreased the immigration of those from southern and eastern Europe, particularly Jewish immigrants (Ludmerer 1972*b*; Allen 1975; Beckwith 1976; Thielman 1985).

The first involuntary sterilization law in the United States was passed by the state of Indiana in 1907 (Dugdale 1877; Punnett 1917; Fisher 1924; Reilly 1983,



1987, 1991). In 1937, Georgia became the 32d and last state to enact a eugenic sterilization law (Larson 1991). It is known that at least 60,000 people were involuntarily sterilized in the United States, and perhaps more than 100,000 were sterilized during the period of the active utilization of these laws. Most states included mental retardation, insanity, and criminality as reasons for involuntary sterilization. However, many states included chronic alcoholism, epilepsy, pauperism, and prostitution, as well as orphans and derelicts (Buck v. Bell Superintendent 1927; Reilly 1983, 1987, 1991; American Academy of Pediatrics, Committee on Bioethics 1990).

A misconception of the German eugenic program is that it started with the Nazis in 1933. In fact, the German eugenic program, racial hygiene (*Rassen Hygiene*), began in the late 19th century when Drs. Wilhelm Schallmayer and Alfred Ploetz began to express their views concerning racial hygiene (Weiss 1986, 1987; Proctor 1988). During the early 20th century this movement became more racist, and when Hitler assumed power in 1933, the program was essentially in place, at which time it received a great stimulus from Hitler and the Nazis (Weindling 1985, 1989, 1993). The first involuntary sterilization law in Germany was passed on July 14, 1933, and was used extensively during the next 12 years, at first to sterilize the "black" children who were born to German girls, as well as the mentally and physically handicapped. This program was later extended to sterilize the various "undesirable" ethnic groups, such as the Jews, Poles, and Russians, who were needed as slave laborers in the factories and concentration camps of Germany. They were therefore sterilized rather than killed in the death camps (Alexander 1949; La Chat 1975; Noakes 1984; Pfaafflin 1986; Müller-Hill 1988).

The popularity of the eugenics movement was enhanced in Germany after World War I by the increased unemployment, the large number of troops returning from the front who could not find jobs, and the terrible depression that engulfed Germany during this period. In both Germany and the United States, the framework for the eugenics movement was the rediscovery of Mendel's laws of inheritance, consequently many of the conditions that were included in their programs were thought to be inherited in a direct way from the parents to the children.

### **Resurgence of Biological Determinism**

The concept of biological determinism indicates that our genes control our destiny and that everything we do

is based solely on our genetic make-up (Allen 1984a, 1984b). During the first third of the 20th century, the concept of biological determinism was used by eugenicists in the United States and Germany to explain many of the social ills of the period, including prostitution, immoral behavior, degeneracy, drunkenness, unemployment, criminality, and chronic alcoholism. These same eugenicists also believed that many medical conditions, such as mental retardation, congenital defects, epilepsy, and IQ, were based solely on our genes. Their ideas and programs were given a foundation by the re-discovery of Mendel's laws of inheritance in the early 1900s, and when these laws were implemented, it gave the eugenicist a basis for expanding the scope to include all of the social ills mentioned above. Using this framework, they then "educated" other professionals, the lay public, and Congress about the impending dangers and devised ways of controlling them, namely, through involuntary sterilization and the Johnson Immigration Act of 1924 in the United States and through involuntary sterilization, euthanasia, and genocide in Germany (Allen 1986; Proctor 1988).

When the USHGP was in the planning stage, some of the scientists involved indicated, particularly in articles to the lay press, that we would now be able to understand the essence of being human, and that they held in their hands knowledge that they could use to control our destinies. Fortunately, other scientists, ethicists, philosophers, and social workers immediately responded that there was more to being human than just our genetic material.

Although the eugenic use of the concept of biological determinism is the primary concern of this paper, there are other medical aspects that need to be briefly mentioned. Most important of these is the concern that if the idea of biological determinism in the etiology of disease prevails, then many environmental factors will be excluded. Examples are the role of cigarette smoking in the etiology of lung cancer and the role of high-fiber diets and high-fat diets in the etiology of colon cancer. Another example would be the exclusion of the role of environmental factors in the etiology of the most common lethal birth defect in the United States, namely open neural tube defects. We know that there are many genes involved in the etiology of open neural tube defects, but most cases are due to multifactorial inheritance, which means that there are many genetic factors that predispose to, and environmental factors that precipitate, the defect. There are many individuals in the population who have genes predisposing to open neural tube defects yet who have a completely normal central



nervous system. If we focused only on the genetic background, we would perhaps miss many important things that we can do to lower the incidence of this serious condition, e.g., supplementing the woman's diet with folic acid beginning at least two months prior to a planned conception (Smithells et al. 1983, 1989; Bower and Stanley 1989; Milunsky et al. 1989; Medical Research Council Vitamin Study Research Group 1991).

### Genetic Discrimination

Genetic discrimination has been defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic construction of that individual" (Natowicz et al. 1992a, p. 466). Natowicz et al. later expanded upon this definition as follows:

genetic discrimination is discrimination against an individual or a member of the individual's family solely on the basis of that individual's genotype. This type of discrimination, like sex, race, age, sexual orientation, and disability discrimination, is unfair because it treats individuals as though they are defined by membership in some particular group. In some circumstances, it is legitimate to make distinctions between individuals on the basis of their individual characteristics. Thus, in making decisions about whether to hire an individual, it is legitimate to consider genetic factors if these factors are relevant to the performance of the job and to the health and safety of others. But, as the law states, in order to avoid illegal discrimination, it is necessary to assess each case individually, and it is necessary that there be no reasonable accommodations that would enable a (genetically) disabled person to perform the job. [Natowicz 1992b, p. 899]

By using the above definition of genetic discrimination, Billings et al. (1992) have found that genetic discrimination exists and is manifested in many social institutions, especially in the health and life insurance industries. Billings et al. solicited cases of possible genetic discrimination by mailing announcements to 1,119 professionals and by placing an advertisement in *The American Journal of Human Genetics*. They received 42 responses and excluded 13 of these because they failed to meet the strict criteria of genetic discrimination that Billings et al. had established. The 29 responses evaluated described 41 incidents of possible discrimination. Of these 41 instances, 32 involved insurance (applications for coverage, changes for health and life disability, mortgage and auto insurance), and 7 involved employment (hiring, termination, promotion, and transfer).

In the past, negative eugenics programs have been established on the basis of pseudoscientific and less specific scientific information than is available today because of the Human Genome Project. It is important that, early in the program, guidelines to protect the privacy, autonomy, and ethical values of each patient are firmly established. The work of the ELSI research team, associated with both the National Institutes of Health and Department of Energy, is tremendously important.

### Is a Resurgence of Eugenics Possible?

The authors believe that a eugenic mentality has existed in the United States during the entire 20th century. It was more apparent in the first 45 years, after which it began to lose its support and popularity because of two primary factors: the first was that many scientists realized that much of the information on which eugenics was based was pseudoscientific; hence, scientists became suspicious of the entire eugenics program. The second factor was the increased awareness by scientists and lay people in the United States of the German eugenics movement and the horrendous deeds that were perpetrated, particularly during the early 1940s. It is interesting that, during this period, some individuals, such as Raymond Pearl and Margaret Sanger, who had been active in the eugenics program became leaders of the population control movement (Haller 1984; Allen 1991). We believe that with the current background and possible changes in the future there is a significant risk that there will be an increased sentiment for instituting eugenic measures in the United States. We have mentioned some of the factors in previous sections of this article but will detail others in the following sections.

#### Race

In the past, most negative eugenics movements have been against various races or ethnic groups. In the United States, the involuntary sterilization laws primarily focused against those in state mental institutions; hence, this group included mostly the poor and blacks. The Johnson Immigration Restriction Law of 1924 was focused against the immigration of "inferiors" from southern and eastern Europe and Asia, as well as blacks and Jews. In Germany, the first major eugenics movement occurred in 1937 when their involuntary sterilization law was implemented against children who were born in Germany immediately after the war to white German women and who were fathered by the black



African troops who were part of the French Foreign Legion (Müller-Hill 1988). These laws were later extended to include at first Jews, and then ethnic groups from eastern Europe, and finally anyone who disagreed with the policies of the German government.

There is still a proeugenics sentiment in the United States regarding the treatment of individuals because of their race or ethnicity. An example is the continued existence in the United States of a very active neo-Nazi movement. This was documented in 1991 by the film *Blood in the Face*, which consisted of a series of interviews and film clips regarding the activities of the neo-Nazi group from the 1950s until the present time. It is very disconcerting to listen to interviews of Americans, dressed in Nazi uniforms and swastika arm bands, who tell of how, with the next revolution, the Jews and blacks in this country will be killed and Hitler's dreams will be fulfilled. It is interesting that one of the individuals who was interviewed frequently during this movie was David Duke, who, at the time, was one of the leaders of the Ku Klux Klan and who, more recently, was a gubernatorial candidate in the state of Louisiana. Duke spoke about his view that the poor were a drain on the existing resources of society.

Some are concerned that different polymorphic markers might be found in the genomes of individuals who are of different racial or ethnic groups, and that these markers could be used in a biased manner supported by genetic technology. One has only to remember the tremendous flap in the 1960s and 1970s over the supposed difference in IQ due to the genetic makeup of blacks versus whites (Jensen 1969). "In the past, this quest was called 'eugenics,' and it had practical as well as scholarly aims. For it hoped to warn people of supposedly superior strains that they should not mate with their genetic inferiors. The fear was of 'mongrelization,' a phrase then commonly used, wherein the best human breeds would marry down and produce lesser heirs. Today, such sentiments are seldom stated in so direct a way. Rather than counseling against intermarriage, it will be hinted that even social racial mixing can have deleterious effects" (Hacker 1992, p. 26).

Another worry is whether the new technology resulting from the work of the Human Genome Project will be available to every American. At present, there are many inequities in health care, including 35 million Americans who are without any type of health insurance and who lack essentials, such as childhood immunizations and prenatal care, that are not being dispensed to the poor in this very affluent country. Will these inequities continue and, in fact, be exaggerated

once the new technologies, which will be expensive, are available to eventually treat genetic disease?

Studies have shown that blacks have a lesser chance of receiving coronary artery bypass graft surgery (Goldberg et al. 1992) and renal transplants (Gaylin et al. 1993) than do whites, and that the uninsured are at greater risk for suffering medical injury due to substandard medical care (Burstin et al. 1992). After the Los Angeles riots of 1991, there was discussion that the way the health-care system there treats poor inner-city populations contributed to the rage that fueled the riot (Cotton 1992). This was refuted (Copperman 1992). There has also been an emerging ghetto underclass that is associated with employed blacks and middle-class blacks (physicians, lawyers, etc.) who are leaving the ghettos for more affluent neighborhoods and hence removing a group that had a stabilizing effect on the ghetto (Wilson 1990). Less serious social problems were used by scientists to promulgate an active eugenics program in the United States in the first 45 years of the 20th century.

#### *Response to Birth Defects*

Existing eugenic attitudes have been experienced by one of the authors (K.L.G.) repeatedly during the past 40 years, and more frequently in the past 10 years, when giving lectures and seminars on genetics to professional and lay groups. Some members of those audiences have expressed indignation at the thought that their tax dollars should be spent on maintaining the existence of children with birth defects or genetic disease or adults with mental retardation or mental illness. These thoughts have a chilling similarity to those expressed both by the early 20th-century eugenicists in the United States and, particularly, in Germany.

Another example was the negative reaction from many people, when a bright, articulate, and successful TV anchorwoman, Bree Walker, became pregnant. Walker has ectrodactyly, which has not affected her career, her marriage, or her life. When she had a child who was similarly affected, there were articles and television talk shows in which individuals expressed their views that she had no right to bring a similarly affected child into the world. The overwhelming response, however, was that her reproductive decisions were her own.

#### *Economics*

In the brief review of the American and German eugenics movements in the preceding parts of this article, we mention the role of unemployment in both of these eugenics programs. At the present time in the United States, there is increased unemployment that might be



heightened during the next several years because of the reduction in the federal workforce, the decreased size of the armed services, and the ongoing reduction in size of both large and small businesses because of the necessity of increasing cost-effectiveness by cutting the number of workers to meet foreign competition. There has been a decrease in federal and state monies, which, together with the increased cost of medical care and the increased financial pressure on third-party carriers, has led to suggestions to minimize health care at both ends of the spectrum, namely, for newborns with congenital malformations and genetic disease (Nolan 1987; Post 1988; Jochemsen 1992; Sauer 1992) and for the elderly who for some reason are incompetent or chronically ill (Smith 1987; Kimball and Cooper 1990; Levinsky 1990; Relman 1990*a*, 1990*b*; Pellegrino 1986). Health-care resources are being drained because of new technologies, and the suggestion of limited care for the elderly has been introduced. This concept of “lives not worth living” developed in Germany during the 19th century and was expanded when the Nazis took over in 1933 (Binding and Hoche 1920; La Chat 1975).

Another concern is the increased pressure to make clinical genetics and genetic counseling cost-effective. There have been demands in Great Britain to audit genetics services; it has been suggested that for a genetics clinic to be funded, it should demonstrate that the birth prevalence of a particular disease or malformation is declining and the termination of pregnancies, because of that disease, is increasing in the population (Chapple et al. 1987; Modell and Kuliev 1989; Royal College of Physicians 1989; Bundy 1990; Clarke 1990*a*, 1990*b*, 1993; Davis 1990; Chadwick 1993). In other words, the notion has now shifted to a cost-effective or utilitarian concept regarding genetic counseling. Traditionally, the goal of geneticists in the United States is to make certain that the patient understands the genetic disease in question, as well as their risk of having an affected child or their chance of having a normal child. The cost-effective attitude of genetic counseling is against the present purpose of most clinics in the United States, namely, that the patient be informed and educated in order to make a decision on the basis of his or her needs and ethical background, not primarily because of economic measures (Robertson 1990; Post 1991; Emson 1992; Post et al. 1992). Utilitarian reasoning was the basis of the Nazi eugenic policy (La Chat 1975). It is not unrealistic, however, to be concerned that, with the increased emphasis for cost-effectiveness, medical geneticists and counselors in the United States will realize that the success of their department, and hence their

security, will depend on the number of procedures (e.g., amniocentesis, chorionic-villus sampling, and sonar) and medical genetics lab tests that they order. This could lead to a resurgence of directive counseling.

### *Social Stigma*

When doing genetic counseling, it is important not to stigmatize either the patient or any members of the family (Garver 1977, 1986). Even a situation involving telling a patient that he or she is a normal carrier of a mutant gene can lead to concern, indicating the need for follow-up counseling. In this situation it is important that, although this particular patient carries a mutant gene, he or she should understand that every individual in the population has 8–10 mutant genes. With more sophisticated and more abundant information that will be delineated by the Human Genome Project, this situation will be magnified more than a 100-fold, and, therefore, the possibilities of stigmatizing our patients will be much greater. Because of this abundance of new technology there will be a greater desire to have “perfect babies” (Robertson 1984; Hubbard 1986; Lipman 1991; Proctor 1991; Holtzman and Rothstein 1992; Resta 1992).

Attaching social stigma to genetic disease is not new. One of the first American eugenicists, Dr. Charles Davenport, devoted much time to the study of Huntington disease (Davenport 1911). Dr. Davenport’s eugenic field workers spent much of their time compiling pedigree studies of Huntington disease patients, which stigmatized both people with Huntington disease and their families (Davenport and Muncy 1916).

Davenport’s work with Huntington disease involved only family studies that were collected by his eugenic field workers. Now that the Huntington disease gene has been mapped, isolated, and cloned from the chromosome 4p16.3 area, many more exact predictions can be established (Huntington’s Disease Collaborative Research Group 1993). Since the Huntington disease gene contains a polymorphic trinucleotide repeat, (CAG)*n*, that is larger than the repeat found in the normal gene, it is theoretically possible to diagnose those who would develop Huntington disease during the entire life span of the individual.

Since the beginning of the 20th century, it has been documented how Huntington disease has been used as the basis of involuntary sterilization laws, and, in Nazi Germany, patients with Huntington disease were discriminated against by an active euthanasia program (Meyer 1988; Harper 1992). It is realistic to suppose that, since Huntington disease was targeted in both the



U.S. and German eugenics programs in the first part of the 20th century and with this more exact technology, these same feelings would surface again. Perhaps the decree will not come directly from the federal or state governments, but it could come indirectly from third-party payers who will exclude these patients from insurance coverage. In the United States it may come indirectly from the federal government through provisions of national health insurance, where individuals who carry the gene are encouraged not to reproduce and are pressured to be sterilized.

In both the American and German eugenics movements, chronic alcoholics were listed as candidates for involuntary sterilization and, in the German eugenics movement, euthanasia. There is some evidence that there is a genetic component to alcoholism (Cloninger et al. 1981; Gordis et al. 1990). A recent study indicates that the D2/*TaqI* allele (A-1) for the dopa receptor gene might be involved in an increasing susceptibility to chronic alcoholism (Blum et al. 1990). However, shortly after this study was published, another showed no consistent association between the D2 receptor gene and a predilection to chronic alcoholism (Bolos et al. 1990). Many physicians believe that there is a genetic predisposition for chronic alcoholism, and, as a result of the Human Genome Project studies, if a marker showing such a correlation is found, it could indicate a person who has an increased risk of becoming an alcoholic. This could be used in a discriminatory way to prevent these people from obtaining health and life insurance or from working in sensitive areas. This is genetic determinism and is an example of genetic discrimination simply on the basis of an individual's genotype and not necessarily related to their phenotype (Uzych 1986; Holtzman 1988; Gostin 1991; Juengst 1991; Dewar et al. 1992; Reilly 1992; Harper 1993). With the new technology that has been developed or will be developed through the Human Genome Project, we could list many other single gene disorders, such as cystic fibrosis, Duchenne muscular dystrophy, or myotonic dystrophy, and many multifactorially inherited diseases, such as some forms of cancer, diabetes mellitus, and open neural tube defects, that could be the basis of discrimination.

#### *Patient Autonomy*

In the recent publication, "Los Alamos Science" published by the Los Alamos Center for Human Genome Studies, two scientists who wrote the section on the ethical, legal, and social implications of the Human Genome Project discussed genetic counseling thus:

"The current standard for the profession is to present information in a non-directive, value-neutral way and in a manner that preserves client autonomy. Essentially this means that the counselor should not project his or her values into the patient. But does this standard work in a practical sense? A patient with a high cholesterol level is not told by his doctor, 'Your cholesterol is 350. It could kill you so gather some information on cholesterol and make whatever decision you want.' The doctor's advice will be much more directive; it is likely to include recommendations about treatments or lifestyle changes that can ameliorate the illness. Those in the genetic counseling profession, however, still cling to the non-directive counselor and autonomous patient model—I believe this model is increasingly untenable" (Friedman and Reichelt 1992, pp. 310–311). This is an inadequate analogy, because when a physician counsels a patient about a high cholesterol level or about a strep throat or most other medical conditions, it does not involve a very important ethical or moral decision by the patient. On the other hand, many medical genetic decisions involve serious questions about prenatal diagnosis, abortion, and sterilization, which have different moral and ethical implications to most patients. These serious moral and ethical decisions have to be made by the patient, with the assistance of the physician, clinical geneticist, or genetic counselor and sometimes with the advice of his or her rabbi, minister, or priest (Garver 1977, 1986).

The autonomy of the patient in making his or her decisions is even more important today than it was 20 years ago because of the increased encroachment of third parties (e.g., state and federal governments, insurance companies, or peers). In the recent article "MSAFP Screening Activities of State Health Agency: A Survey" the authors stated, "by its very nature, MSAFP testing is the kind of program that lends itself to a state or regional public health approach" (Cunningham and Kizer 1990, p. 901). This was answered by a letter to the editor, that pointed out the possible negative eugenic implications of this public health approach because of the demands for cost-effectiveness in most government programs (Garver 1991).

#### *Prenatal Diagnosis*

Some have mentioned that prenatal diagnosis and selective abortion of fetuses with malformations or genetic disease is a form of negative eugenics (Hubbard 1986; Garver and Garver 1991, 1992; Resta 1992). When prenatal diagnosis was first introduced, only serious lethal conditions were diagnosable (e.g., chromo-



somal abnormalities and serious biochemical abnormalities). As the sophistication of both prenatal diagnosis and molecular genetics has increased, more less-serious diseases can now be diagnosed prenatally (e.g., phenylketonuria and cystic fibrosis). There is growing awareness that, as we go into the 21st century, it will be possible to pick out many normal variants and social predispositions that can be screened prenatally, and if they are either present or absent, depending on the wishes of the parents, the fetus could be aborted.

### Conclusion

It is important to emphasize the value of every individual in the community, regardless of race, ethnic group, or physical problems, for it is in this climate that our rights are preserved. History repeats itself, and the finger of blame has always pointed to the other person or other nation. That finger should turn to the self, to enlighten one to look positively and constructively at the human family.

The recommendations of the ELSI committee will be helpful as a framework for introducing new genetic technology in a way that avoids the mistakes of the past. Society has to recognize the subtle factors, as reviewed in this article, that led to the active eugenics programs in the United States and Germany during the first part of the 20th century. Similarities and differences between races and ethnic groups should be discussed and understood. Unemployment and poverty were considered social ills that were supposedly correctable by eugenic measures by the early eugenicists, but we should now realize that these problems can be solved by economic and educational measures. Prenatal diagnosis, a new form of negative eugenics, is becoming a routine part of prenatal care. It is vital that the growing desire to have “normal” babies does not erode our acceptance and care of those who have disabilities, otherwise the advances made through the Americans with Disabilities Act will be nullified.

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