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# ASHG STATEMENT
# Eugenics and the Misuse of Genetic Information to Restrict Reproductive Freedom

Board of Directors of the American Society of Human Genetics

## Introduction

The global scientific community is making extraordinary advances in understanding the human genome. This knowledge has contributed many important medical benefits. Yet, concern about the possibility of misuse of genetic concepts and genetic information may be as great today as at any time since World War II. Many fear that as we learn more about how genes vary and function, some individuals or institutions may be tempted to ascribe an overly deterministic influence to their role in shaping human health and potential and to pursue social policies that limit or constrain reproductive freedom. Therefore, the Board of Directors of the American Society of Human Genetics reaffirms its commitment to the fundamental principle of reproductive freedom and unequivocally declares its opposition to coercion based on genetic information.

## Statement

The American Society of Human Genetics recognizes that genetic variation can significantly influence risk for disease and the nature of an individual's future health and that many human capacities and talents are influenced by genes.

The American Society of Human Genetics deplores laws, governmental regulations, and any other coercive effort intended to restrict reproductive freedom or to constrain freedom of choice on the basis of known or presumed genetic characteristics of potential parents or the anticipated genetic characteristics, health, or capacities of potential offspring.

The American Society of Human Genetics recognizes the need for international cooperation to protect reproductive freedom and stands ready to work with colleagues in and outside the field of human genetics to achieve this goal.

The American Society of Human Genetics believes that the best way to prevent genetic information from being used to restrict reproductive freedom is to educate the public (in particular, those directly involved in setting public policy) about the scope and limitations of our understanding of genetics and genetic tests. It is especially important that individuals be educated about how to ask for and obtain appropriate genetic information and that health care providers be educated to assist them.

## Background

### A Note on Language

The drafting of this document was complicated by the substantial variations in meaning given to the word "eugenics." Ultimately, the drafters decided to de-emphasize that word. Yet, because on many occasions during this century scientifically unsound and socially harmful policies have been implemented in many nations in the name of eugenics, a comment on the term is warranted.

When Francis Galton (1883) coined the term eugenics, he took it from the Greek: "eu" means "good," and "genic" derives from the word for "born." Galton defined it as "the science of improvement of the human race germ plasm through better breeding" (p. 14). At the height of the eugenics movement in the 1920s, the *Encyclopaedia Britannica* (1926) entry on eugenics emphasized that the term connoted a "plan" to influence human reproduction. A typical modern dictionary definition is "a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed" (*Webster's,* 9th ed.). Although it is not apparent from the dictionary definition, the word has a pejorative connotation and is frequently used when referring to governmentally driven policies to limit reproductive freedom.

Knowledge-based decisions made by individuals or couples to avoid the birth of a child with disease or disability, as long as they are not unduly influenced by coercive governmental, institutional, or other policies, are acceptable.

Many public health practices to improve the health of living or future people have been implemented, to achieve laudable goals. Some examples include newborn

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screening programs to identify infants with disorders for which early treatment is beneficial, the provision of prenatal diagnostic services, maternal vaccination for rubella, the addition of folic acid to food to reduce the risk of certain birth defects, and warnings on alcohol or cigarette labels about the potential for damage to the fetus. The American Society of Human Genetics views prenatal screening and diagnostic programs, including those undertaken with the knowledge that an individual who chooses to be tested may seek selective termination of pregnancy, as acceptable as long as individuals are not coerced.

### *Historical Note*

Many nations have a history of eugenic thought or practice based on perceived genetic risks. It is important to note that such practices were based on little or no scientifically defensible beliefs. Some have tried to keep gene pools separate by forbidding unions between members of different social groups. For example, the caste system in India may represent the largest such eugenic program ever, spanning almost 2,500 years (Dobzhansky 1973). Antimiscegenation laws in the United States, which appeared as early as 1630 in the colonies and existed until they were struck down as unconstitutional in 1967, were premised in part on the erroneous notion that interracial marriage produced children of reduced genetic quality.

Galton used the word eugenics to characterize efforts to produce children who would be well born. However, he did not merely desire that as many infants as possible be born healthy. His real goal was to ensure that as large a fraction as possible of each generation would be the offspring of what he considered the best “stock.” By 1883 Galton, who then had been studying human heredity for almost 20 years, was convinced that the British upper classes were having too few children to maintain what he considered their crucially important contribution to the gene pool of Victorian England. He exhorted the upper classes to have more children. Over the next 30 years this idea garnered much interest. Among its most famous proponents in the United States was President Theodore Roosevelt, who warned that the failure of couples of Anglo-Saxon heritage to have large enough families would lead to “race suicide” (Reilly 1991). Roosevelt’s support of eugenic ideals reflects the popular appeal of eugenics during the first half of this century. Adherents included liberals and conservatives, progressives and libertarians. In the early decades of this century the emphasis on encouraging reproduction among those assumed to possess a superior genetic endowment became known as “positive eugenics.”

The term immediately suggests a contrasting policy—“negative eugenics”—which emerged at about the same time. The goal of negative eugenics is to restrict parenting by “undesirable” individuals, presumably because of a strong likelihood that their children would be “unfit.” During the first half of the twentieth century, the United States implemented two negative eugenics programs. The United States immigration policy that was erected in the 1920s and dismantled in 1968 favored immigrants from northern and western Europe. This policy was rationalized during congressional testimony by a self-described eugenics expert who strongly favored the quota system that became the centerpiece of the law (Reilly 1991). The United States never enacted a federal sterilization statute, but ~30 states did, many after the Supreme Court upheld a Virginia law that permitted state officials to sterilize institutionalized retarded persons whom a physician determined likely to become the parent of children with similar deficits (*Buck v. Bell,* 274 U.S. 200 [1927]). Between 1907 and 1960 in the United States at least 60,000 people were sterilized without their consent, pursuant to these state laws. During the 1930s, the heyday of these programs, ~5,000 persons were sterilized each year. The majority were young women for many of whom the evidence of genetically caused mental retardation was poor or nonexistent (Reilly 1991). Geneticists were not active participants in these programs; with few exceptions, however, neither were they public critics.

England never enacted an involuntary sterilization law nor launched a coercive private effort. In Canada, the province of Alberta was strongly influenced by sterilization programs in the United States. Alberta had an active program during 1928–60 pursuant to which several thousand people were sterilized (Caulfield and Robertson 1996). A class-action lawsuit by many of the surviving individuals was recently settled with the government (*Muir v. Alberta,* Alta. L. R. 3d 305 Alt. Q. B. [1996]).

Although arguments for maintaining racial purity abound in nineteenth century German literature, the Nazis were also influenced by events in the United States. The 1934 German racial hygiene law relied on a model bill written by the American eugenicist Harry Hamilton Laughlin, who directed for three decades the Eugenics Record Office at Cold Spring Harbor. In its first full year of operation the Nazi program dramatically eclipsed activities in the United States, sterilizing ~80,000 persons without their consent. The much grander scope was achieved because the Nazi law applied to the entire population (rather than to institutionalized persons), created a system of “hereditary-health courts” designed exclusively to hear and process petitions for sterilization, and permitted petitions proposing that an individual be sterilized to be filed by a broad range of citizens.

The German sterilization program quickly evolved to target and eliminate retarded and epileptic children, the mentally ill, and other groups. The program has been called a precursor to the gas chambers. During the early years (1934–38) the Nazi sterilization program was not primarily an attempt to improve the gene pool. It focused on eliminating "useless eaters"—persons who would consume resources without contributing to their production. One exception was persons with Huntington disease. A stated goal of the Nazis was to sterilize as many persons at risk for this disorder as possible, to improve the gene pool. The Nazi sterilization program owed part of its success to the efficiency with which the government maintained patient registries, which made it comparatively easy to locate persons with various disorders (Burleigh 1994).

Often overlooked in discussions of Nazi eugenic practices are the sterilization programs that were implemented during the 1930s in other European countries (Adams 1990) and in other nations around the globe. In smaller nations (e.g., Sweden, which had an active eugenic sterilization program until the 1960s), the impact of the programs was proportionately greater than that in the United States.

After World War II (1948) Japan passed a Eugenic Protection Law that permitted the sterilization of persons who had even distant relatives with any one of ~30 conditions presumed (in most cases, erroneously) to be inherited (Tsuchiya 1997). Japan's law was amended in 1996, in part to remove the term eugenic. We have no firm evidence that it was applied coercively.

In the past 20 years a few governmentally supported public health programs have focused on reducing the number of births of children with specific disorders. In some cases voluntary public response to these programs has led to a substantial reduction. Examples include the rapid decline in the United Kingdom in the number of children born with neural tube defects (Cuckle and Wald 1987) and the public health campaigns to reduce the number of children born with $\beta$-thalassemia in Sardinia (Cao et al. 1989) and Cyprus (Angostiniotis et al. 1986).

### *Current Programs that May Restrict Reproductive Freedom*

There are few public health programs operating in the world today that may be said to use genetic information to restrict reproductive freedom. Singapore has implemented a policy of using economic incentives to encourage reproduction by educated women and to encourage sterilization among uneducated, poor women, but it does not rely on genetic information and is not mandatory (Chan 1985).

China's Maternal and Infant Health Care Law (Law of the People's Republic of China 1994) has aroused concern because it appears to require medical counseling before marriage for people whose families have a relative with one of a listed group of conditions (including mental illness, epilepsy, and mental retardation) that the law presumes (with little or no scientific basis) are hereditary. The law (the official translation of which involves nuances of language that complicate analysis) also has been construed to require sterilization or long-term contraception as a precondition of marriage if a person is determined by the doctor to be at risk for bearing an affected child. Another section of the Chinese law appears to require that couples at risk for certain disorders must undergo prenatal diagnosis and follow the directive of the attending physician.

However, the law includes no penalty for noncompliance and (to the best of our knowledge) is not enforced. It seems to represent a "standard of care," albeit highly directive, to which the government aspires rather than a rule of conduct that must be obeyed. The official English translation of the law uses the word "shall" in a manner that connotes compulsion, but some Chinese bioethicists insist that it is meant to connote "ought"—that is, an ethical obligation, rather than a legal rule (R.-Z. Qiu, personal communication). China's human geneticists, recognizing the importance of even symbolic language that seems to embrace eugenics, have requested that the central government change the law to comply with international concern and to acknowledge the centrality of voluntary choice in genetic testing and counseling (Yang, in press). Taiwan has had a similar law on its books for several years, which has neither been enforced nor drawn international criticism.

Many governments support programs, in the interests of improving the odds that children will be healthy. Some are mandatory. In our view, none involve the misuse of genetic information. Examples include (1) programs to encourage or discourage the number of births among the entire population; (2) laws that try to protect the fetus from environmental harm (e.g., warnings on cigarette packages about the risk of smoking during pregnancy); (3) laws that implement newborn genetic screening programs; (4) laws or regulations that fund genetic services, including genetic counseling, genetic testing, prenatal diagnosis, and the provision of special diets for newborns with certain inborn errors of metabolism (Cunningham 1998); and (5) laws forbidding marriage between first cousins and other consanguineous unions.

## Conclusion

Efforts to implement programs that restrict reproductive freedom based on genetic information are scientifically and ethically unacceptable and should be challenged. Although it is sometimes possible to ascertain the risk of bearing a child with a genetic disorder, for the majority of pregnancies it is not possible to make predictions about a future child's health or other capacities. Misguided efforts to do so devalue humanity.

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