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## **Eugenics, Euthanasia and Genocide**

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#### Introduction

As physicians or health care providers we should be concerned with the history of eugenics. However, as George Wilhelm Hegel has commented, "What experience and history teach is this — that people and governments never have learned anything from history, or acted on principles deducted from it" (The Oxford Dictionary of Quotations 195, p. 240). If this is so, and certainly it appears to be, with the strong emergence of public attitudes regarding "The Right to Die," then we have a duty as physicians to guide the public toward a commitment for the sanctity of life.

The distinction should be made between genetics and eugenics. Genetics is a legitimate scientific study of heredity. Eugenic comes from the Greek word, eugenes (eu-well and genos-born). The term refers to improving the race by the bearing of healthy offspring. Eugenics is the science that deals with all influences that improve the inborn quality of the human race, particularly through the control of hereditary factors. A eugenic decision is an action or contemplated action inspired by concern for the genetic well-being of a single individual, whether that individual is an adult, child, fetus or anticipated future conception. A eugenic program is a public policy structure designed to have its affect on gene frequencies in whole populations. Negative eugenics is a systematic effort, whether decisional or programmatic, to minimize genes that are considered deleterious. Positive eugenics is a systematic effort, whether decisional or programmatic, to maximize genes that are considered desirable. Another term that is relative is genocide, which is the deliberate extermination of an entire human ethnic, political, or cultural group.

There are many misconceptions concerning eugenics. The first is that it has only been an issue in the 20th Century. However, like most aspects of the art of medicine, the origin or eugenics goes back at least 2,500 years when it was practiced in the ancient city of Sparta. Shortly after birth, the newborn child was brought before the elders of the city who decided whether it was to be reared. If the child was defective or weakly, it was taken to the mountains and either left to be exposed to the elements and animals, or in some cases, thrown into a deep ravine to be instantly killed. This is an early example of negative eugenics.

The second misconception is that eugenics started with a misuse of gentics by the Nazis, and the coming into power of Adolf Hitler and the National Socialist Party in 1933. However, if one considers the Race Hygiene movement in Germany,<sup>2,3</sup> it is evident that it was very active in the late 19th century, and was promulgated by physicians such as Alfred Ploetz and Wilhelm Shallmayer. Also, most major countries have had a eugenics program; thus it is a world-wide phenomenon.<sup>4</sup>

The third misconception is that all eugenics was popularized by the rediscovery of Mendel's laws of heredity in the early 20th century. Although this may have stimulated the movement in many countries, several countries rejected Mendelism. Countries such as Russia, France and Brazil believed in Lamarckism as their basis for heredity, but also had active eugenics movements.<sup>4,5</sup>

The formal study and application of eugenics as we know it today was founded by Sir Francis Galton, who coined the word **Eugenics** in 1883 to describe the science for the biological improvement of the human race.<sup>6-8</sup> Galton was convinced that a wide range of human physical, mental and moral traits were inherited. He, therefore, reasoned that progress of the human race depended on improving the selective transmission of the population's hereditary endowment in future generations.<sup>9-13</sup>

Sir Francis Galton's ideas of eugenics developed slowly until the early 1900's, largely because of the lack of any solid scientific theory of inheritance on which to build his premise. However, in the early 1900's Mendel's laws of inheritance were rediscovered and applied to human genetics, and this opened up an entirely new set of principles on which to study inheritance in human beings. 14,15 During the first four decades of the 20th century, a world-wide eugenics movement developed which has been frequently described and analyzed for the United States, England and Germany. However, many other active eugenic movements were present during this time in other countries including France, Brazil, Russia, Norway, Denmark, Finland, Sweden, Austria, Mexico, Argentina, Cuba and Singapore. These eugenic movements provide an excellent opportunity to examine and analyze the relationship between science and its social/political context. It also demonstrates how different racial, ethnic and religious prejudices can influence eugenic decisions and allow them to be grossly misused.

In this article on eugenics, only the American and German eugenics movements will be reviewed. Thought will be given to what we are doing today, and what we might be doing in the future in regard to eugenic actions.

## **Eugenics Movement in the United States**

The movement in the United States was nourished by the rediscovery of Gregor Mendel's laws of inheritance in the early 1900's and the mistaken belief that all or at least most human characteristics could be genetically classified as passing down from parent to offspring. <sup>16-19</sup> It was also felt that the gene was a unit that would not change, hence predictions could be made about the genetic worth of children by looking at the genetic worth of their parents. It was the belief of biologists that many human conditions such as feeble-mindedness, congenital defects, epilepsy and other diseases were inherited by direct transmission, and hence, could be controlled by the use of negative eugenics. <sup>20-22</sup> During the first part of the 20th century in the United States, there was increasing concern about social issues. <sup>23-29</sup> Such subjects as degeneracy, drunkenness, unemployment, criminality, prostitution and chronic alcoholism were believed to be genetically related, and hence, could be controlled by eugenic measures. <sup>20-22,30</sup>

With this scientific and social background, there was an increasing number of 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. These factors all nurtured an increased interest in eugenics.<sup>31-37</sup>

Perhaps the most important stimulus for a formal eugenics program in the United States was the establishment of the Eugenics Record Office (ERO) at Cold Spring Harbor, Long Island in 1910.<sup>38</sup> The ERO was associated with the Station for the Experimental study of Evolution (SEE), which had been established in Cold Spring Harbor in 1904 with the financial support of the Carnegie Institution. The SEE was a leading laboratory for the study of experimental genetics with particular reference to Man.

Dr. Charles Benedict Davenport was one of the early leaders of the eugenics movement in the United States. Dr. Davenport served as an instructor at Harvard until 1899 when he accepted an assistant professorship at the University of Chicago where he remained until 1904. At that time, he persuaded the Carnegie Institution of Washington to fund the station for the experimental study of evolution with himself as director. Dr. Davenport realized the need to enlarge these facilities for a more comprehensive approach to human genetics, and in 1910, he persuaded Mrs. Mary Williamson Harriman to help enlarge the program by establishing the Eugenics Record Office at Cold Spring Harbor. Mrs. Harriman was euthusiastic about the idea, and contributed a mansion and almost 75 acres of land for the site of the facility. She initially agreed to fund the complete operating expenses of the ERO for at least five years.

Another individual who contributed to the early eugenics movement in the U.S.A. was Harry Hamilton Laughlin, who was recruited by Davenport from the agricultural department of the State Normal School in Kirksville, Missouri, to become superintendent of the ERO.<sup>39</sup> Davenport and Laughlin were immediately attracted to each other because of their common interests in agricultural breeding, particularly involving various mammals. The ERO had two general purposes. The first was to carry out research in human heredity, especially the inheritance

of social traits and the second was to educate lay persons about the importance of eugenic research and the implications of eugenic findings for public policy. During the next several decades, Davenport and Laughlin worked tirelessly to advance the cause of eugenics scientifically, and in particular to lecture both the professional and lay public about the potential use of eugenics to better the race.

The first issue of Eugenical News was published in 1916 with both Davenport and Laughlin as editors. It contained short, popular articles reporting on eugenic research, "the menace of the feeble-minded," differential fertility (in that the underprivileged were overproducing in comparison to the better-educated), the evils of race-crossing as well as reviews of books on eugenics. The ERO also helped to publish popular and semi-popular works of other eugenicists who were not directly connected to the institution. One of these was Madison Grant, a wealthy New York lawyer-conservationist, member of several public commissions, and author of one of the most racist, pro-Nordic books written during the period, The Passing of the Great Race. The ERO, particularly Laughlin, worked tirelessly to popularize eugenics by sponsoring exhibits, lectures, and articles in popular journals and newspapers. Laughlin effectively lobbied Congress for the passage of the Johnson Restrictive Immigration Act of 1924.

## Johnson Immigration Restriction act of 1924

An open door immigration tradition had existed for people of most nationalities to the United States until 1921. At the close of World War I, there had been an initial attempt to pass an immigration restriction law based largely on economic positions. A temporary measure was passed in 1921 to combat unemployment resulting from the slow-down of the economy and the return of soldiers from the Front. Between 1921 and 1924, however, eugenicists, in conjunction with the Immigration Restriction League, worked for the passage of a more comprehensive and permanent law.<sup>40,41</sup>

Laughlin played an important role because of his appointment in April, 1920, as the expert eugenics agent of the House Committee on Immigration and Naturalization.<sup>39</sup> During the debates over immigration restriction, he appeared before the committee on several occasions always presenting the view that the biologically inferior new immigrants were threatening to wipe out the native American stock. Laughlin's evidence for such a statement was unjustified by the facts which he brought forth. He included references to the persistence of degeneracy in immigrant families, to their low scores on IQ tests, and to claims that conditions such as shiftlessness, alcoholism and insubordination were genetic traits appearing far more frequently in the foreign-born, than in the native American. One member of the Committee on Immigration and Naturalization insisted that another geneticist be heard and Herbert Spencer Jennings of Johns Hopkins was finally called to testify. However, Jennings, who was a strong opponent of the eugenics movement was given only five minutes to testify on the final day of the hearings. If given more time, Jennings could have discredited some of the earlier testimony and explained that the IO tests were given in English to

immigrants who, in many cases, could not speak or read the language.

There were significant differences in the House on how to regulate immigration, and much debate as to whether to use the 1890, 1900 or 1910 census as the basis for setting quotas. The difference was in the changing patterns of immigration from Europe during this period and the fact that there was an increase from the 1880's onward of people from southern, central and eastern Europe. After much debate, the agreement was reached to base immigration on the 1890 census. This interpretation greatly favored immigration of the so-called Nordic or Anglo-Saxon stock, namely, people from north-western Europe and Great Britain in preference to those from southern Europe, eastern Europe, and particularly, Jewish immigrants. Like Madison Grant, Laughlin felt that immigrants from southern and eastern Europe, especially Jews, were so racially different from, and genetically inferior to the current American population that any racial mixture would be deleterious.<sup>24</sup>,<sup>25</sup>

The passing of the Johnson Restrictive Immigration Act of 1924 was perhaps the greatest triumph for the American eugenics movement, particularly for Laughlin, Davenport and the ERO. In retrospect the passage of the Johnson Restrictive Immigration Act can be seen as the misuse of pseudo-scientific and incorrect genetic information.

## Eugenic Sterilization Laws in the U.S.A.

Interest in eugenic sterilization in the United States began in the late 19th century because of concerns about criminals, the insane and feeble-minded persons.<sup>42,43</sup> This quickly expanded to include alcoholics, paupers, orphans, derelicts, delinquents, prostitutes and those unable to support themselves.<sup>25</sup> At first, reformers were optimistic about helping such individuals. However, by the end of the century more reformers came to believe that these conditions resulted from deficient heredity, and thus could not be ameliorated or eliminated by environmental procedures. An important event preceding the rise of sterilization programs was the publication of a study in 1875 of the Jukes, a New York family with a propensity for Alm houses, taverns, brothels and jail.<sup>44</sup> This was followed in 1912 by the publication of an immensely popular study of the Kallikakas family, which had an eminent line and a degenerative line running in parallel over many generations.<sup>30</sup> This book did much to rationalize principles of negative eugenics.

During the 1890's, campaigns for legislation which would prescribe the sterilization of the "unfit" were begun. In 1897 a bill calling for the castration of the feeble-minded and certain criminals was introduced and discussed in the Michigan State legislature where it was ultimately defeated. Some institutions proceeded to sterilize without legal authorization. For example, at the Kansas State Institution for Feeble Minded children, Dr. F. Hoyt Pilcher castrated 44 boys and 14 girls before strong public disapproval forced him to stop. 37,45-48

An easy and relatively safe procedure for sterilization of males by vasectomy was first published by a young Chicago surgeon, Ochsner, in 1899. In 1902, Sharp, a surgeon at the Indiana Reformatory, reported a large study on the effects of vasectomy. This operation made it easy for the eugenicist to sterilize males.

However, salpingectomy, the surgical closure of fallopian tubes was not yet perfected as a surgical operation. The eugenicist had little choice but to support long term segregation of feeble-minded women.

In 1907, Indiana became the first state to pass an involuntary sterilization measure based upon eugenic principals. This law required the sterilization of inmates of state institutions who were insane, idiots, imbeciles, feeble-minded, convicted rapists or habitual criminals. This procedure had to be recommended by a board of experts. By 1931, despite strong opposition by the Roman Catholic Church and many concerned citizens, 30 states had passed involuntary sterilization measures. Some of these laws applied to a very wide range of "defectives" including, "sexual perverts, drug fiends, drunkards, epileptics, and diseased degenerate persons." A sterilization bill had been passed by the Pennsylvania legislature in 1905, but was vetoed by the Governor.

Analysis of surveys conducted by the Human Betterment Foundation permitted minimum estimates of mass sterilization and compiled some striking conclusions<sup>46</sup>: 1) Between 1907 and 1963, there were eugenical sterilization programs in 30 states. More than 60,000 persons were sterilized, based on these state laws. 2) Although sterilization reached its peak during the 1930's, several states vigorously pursued involuntary sterilizations throughout the 1940's and 1950's. 3) At any particular time, a few programs were much more active than the rest. In the 1920's and 1930's California and a few mid-western states were most active. After World War II several southern states accounted for more than half of the involuntary sterilizations performed upon institutionalized persons. 4) Beginning about 1930, there was a dramatic rise in the percentage of women who were sterilized. 5) Revulsion against the Nazi sterilization policy seems not to have curtailed American sterilization programs. Indeed, more than one-half of all eugenic sterilizations occurred after the Nazi program was fully operational. The Human Betterment Foundation survey strongly suggested that the total number of sterilizations performed upon institutionalized persons was under-reported.

During the 1960's, the practice of sterilizing retarded persons in state institutions virtually ceased, but still the laws remained. In 1961, there were eugenic sterilization laws in 28 states. There has been a trend to repeal the laws, and as of 1987, eugenic sterilization of institutionalized retarded persons was permissible in 19 states, but the laws are now rarely invoked. A few states have even enacted laws that expressly forbid sterilization of persons in state institutions.

During the last 10 years, the discussion of sterilizing the mentally retarded is no longer in a genetic context. The main issue now is how to protect the incompetent person, and the right of that person to be sterilized. The courts must be convinced that the operation will benefit the patient.<sup>50,51</sup>

In reviewing the history of eugenic sterilizations in the United States, it is evident that many mistakes were made since thousands of persons were forcibly sterilized who were not mentally retarded. Indeed, law suits have resulted from these mistakes. It is also apparent that many individuals were involuntarily sterilized mainly because of their race (Black) or because of poverty and their inability to pay for the care of themselves and their children.<sup>37,46,49,51</sup>

It is disconcerting that these laws were passed by elected representatives of our

government. The Johnson Restrictive Immigration Law was discussed, debated and passed in the United States Congress and then signed into law by our President, Calvin Coolidge. The involuntary sterilization laws were similarly acted on by the State representatives and Senators, and then signed into law by the Governors.

It is distressing that the above duly elected, supposedly intelligent and informed Federal and State lawmakers could have passed such laws. To be charitable, we can assume that they were misled by the incomplete and biased information given to them by their "expert" eugenicist. It would be more distressing if we accepted the alternative reason, namely, that these elected representatives were turning their backs on the constitution and the spirit of America by expressing their own racism and bias.

## **Eugenics in Germany**

To fully understand the German eugenics program, it is necessary to discuss the interaction of euthanasia, eugenics, genocide and medical experimentation in the concentration camps. There are many misconceptions concerning the German eugenics program. The first and most serious is that the program started with the beginning of the Nazis' political control in Germany in 1933. In reality, the movement can be traced to the later part of the 19th century when Drs. Wilhelm Schallmayer (1857-1919) and Alfred Ploetz (1860-1940) began to express their views concerning racial hygiene ("Rassenhygiene").2,3,52 Drs. Schallmayer and Ploetz are regarded as the founders of the German eugenics movement. The early interest in racial hygiene in Germany was stimulated first by social problems caused by rapid and progressive industrialization.53,54 Secondly, concern about the concepts of social Darwinism in which they felt that the more elite, and "therefore better segments of the population" were underproducing in comparison to the working class elements.55 They also realized that the various German wars were a counter-selective process since the "flower of the nation" was going off to war and being killed, while the men who were rejected by the army were at home reproducing. Initially, the racial hygiene movement had no true racist or political overtones, but was merely concerned about the future of the German race and German nation. Many other race hygienists built on the foundations laid by Schallmayer and Ploetz; these included: Max von Gruber (1853-1927), Ernst Rudin (1874-1952), and Fritz Lenz (1887-1976). Later, others used race hygiene as a basis for a more eugenic approach and included Herman Muckermann (1877-1962), Arthur Ostermann (1876-1943), Alfred Grotjhn (1869-1931), and Eugen Fischer (1874-1967).

Another misconception is that the Nazi eugenics policy was mainly a political policy promulgated by the Nazi SS. The truth is that early on in the Nazi movement in Germany, many physicians, particularly young physicians, joined the party in great numbers. After 1933 when the Nazis came to power, the zeal of the young physicians to identify themselves with Nazism continued to an extent that they were the largest professional group. <sup>56</sup>, <sup>57</sup> As the Nazi party began to promulgate their ideas concerning race hygiene, physicians readily endorsed the

movement and accepted the mission of changing their role from "Doctor to the individual," to "Doctor of the Nation." During the years after the Nazi ascension to power, there was a change in attitude of the physicians from recognizing all life as valuable to that of life not worth living. The early biological and intellectual racial hygiene movement in Germany developed into a political-racial hygiene movement designed to demonstrate supposed difference in value of the various population groups.<sup>2,52</sup>,<sup>58</sup>

In Germany, the rediscovery of Mendel's work at the beginning of the 20th century was an impetus that was used by eugenicists to help formulate true eugenic policies. They used Mendel's theory to indicate the inheritance patterns of many of what they claimed were undesirable traits, such as mental retardation, mental illness, criminality, drunkenness, prostitution and poverty. The first journal to deal with eugenics, *The Political-Anthropological Review*, was founded by Dr. Woltmann, a gentleman-scholar, in 1902. Two years later, in 1904 Dr. Ploetz founded the *Archives of Race-Theory and Social Biology*, and in 1905 Dr. Ploetz established the Society of Race-Hygiene.

## Race Hygiene (Rassenhygiene)

One of the first intrusions of German eugenic ideas into private life came in 1908 when, in the German colony of south-west Africa, all existing mixed marriages were annulled and forbidden in the future, and the Germans involved were deprived of their civil rights. This episode is described in 1913 in Dr. E. Fischer's book, *The Bastards of Rehoboth and the Problem of Miscegenation in Man* ("Die Rehobother Bastards und das Bastardisierungsproblem beim Menschen"). In it he writes about the people of mixed blood in German Southwest Africa: "We should provide them with the minimum amount of protection which they require for survival as a race inferior to ourselves, and we should do this only as long as they are useful to us. After this, free competition should prevail and, in my opinion, this will lead to their decline and destruction."

The ideas of race hygiene became relevant to Hitler after he read the second edition of the textbook by E. Baur, E. Fischer and F. Lenz, *The Principles of Human Heredity and Race-Hygiene* ("Menschliche Erblichkeitslehre und Rassenhygiene"), while imprisoned in Landsberg. He subsequently incorporated these racial ideas into his own book, *My Struggle* (Mein Kampf). A chair in "racial science" was established at the University of Jena in 1930. Its first occupant, Hans Gunther, wrote a book in 1929 on this topic, that sold 272,000 copies between 1929 and 1943 (Klein Rassenkunde des Deutscher Volkes).

The possibilities for legislating on race protection were discussed at the 37th Meeting of the Criminal Law Commission on June 5, 1934. Professor Dahm said: "Ideally, sexual relationships between Aryans and non-Aryans should be punished." On June 25, 1934, Dr. Lenz, at a meeting of the Expert Advisory Council for Population and Race Policy, said: "As things are now, it is only a minority of our fellow citizens who are so endowed that their unrestricted procreation is good for the race." 59

A decree of the Ministry of the Interior on February 6, 1936 stated that a system

of records be set up to cover hereditary-biological data on all patients in mental hospitals and institutions. To us this might seem like a perfectly logical way of getting data to evaluate hereditary traits. It is only after we see how this was misused that we realize the possible consequences of their actions.

On June 20, 1939, Dr. Fischer stated in a lecture: "When a people wants, somehow or another, to preserve its own nature, it must reject alien racial elements, and when these have already insinuated themselves, it must suppress them and eliminate them. The Jew is such an alien, and therefore, when he wants to insinuate himself he must be warded off. This is self-defense. In saying this, I do not characterize every Jew as inferior, as Negroes are, and I do not underestimate the greatest enemy with whom we have to fight. But, I reject Jewry with every means in my power, and without reserve, in order to preserve the hereditary endowment of my people." 59,60

RuSHA was the head office for Race and Settlement. As an agency of the SS, it included the Race Bureau and Marriage Bureau. Among the functions of the Race bureau was to decide on the "Aryan qualities" of individuals belonging to conquered nations and their potential for "Germanization." The Marriage Bureau conducted medical examinations of SS candidates and of their brides before marriage. In both cases, applicants were required to produce documentation of Aryan ancestry going back to 1800.

#### Euthanasia

In Germany "Mercy Killing" began to be openly discussed in intellectual circles in the last decade of the nineteenth century. 55,56,60 In 1895 Adolf Jost published a book, "The Right to Death" ("Das Rech auf den Tod") which promoted direct medical killing and indicated that control over the death of the individual must belong to the state.

The jurist Professor Binding and the psychiatrist Professor Hoche published a book in 1920, *The Sanctioning of the Destruction of Lives Unworthy to be Lived* ("Die Freigabe der Vernichtung Lebensunwerten Lebens"). To our knowledge, this is the first time that the Germans used this phrase that became a standard during the Nazi eugenics movement. This book included as "unworthy life" not only the incurably ill, but also the mentally ill, the feebleminded, the retarded, and deformed children.<sup>61-63</sup>

On August 7, 1929, Adolph Hitler spoke in public of killing German infants with physical defects — a slaughter, he estimated, of 700,000 children annually. Most other scientists in Germany felt that this was a tremendous overexaggeration of the number of children with mental retardation and other birth defects.

Germany's euthanasia program began with the destruction of children born with birth defects, mental retardation and genetic disease. A prototype case occurred in the Fall of 1938, and involved a child who was born blind, retarded, and without an arm and a leg. The child's father appealed directly to Hitler, asking that the child be granted a mercy death. At Hitler's request, Dr. Karl Brandt consulted with the child's physician to ascertain whether or not the facts were

correct. Hitler then instructed Brandt that if the report was accurate, that he was in power to allow the child's physician to grant the child euthanasia. The facts were correct and the child was granted euthanasia. This case provided a model in which other infant and child euthanasia actions could be carried out.<sup>63</sup> Dr. Brandt was then directed by Hitler to establish an advisory committee to prepare for the killing of deformed or retarded children. The project was organized under the name, Committee for the Scientific Treatment of Severe Genetically Determined Illness. On August 18, 1939, this committee produced a secret report delivered to all state governments, asking that midwives or doctors delivering any child with congenital deformities, such as idiocy or mongolism, microcephaly, hydrocephaly, missing limbs, malformations of the head, spina bifida, spastics, etc., register that child with local health authorities.<sup>60</sup>

The data from these births were tabulated on questionnaires which were returned by the physicians or midwifes to Berlin. Here, they were examined by a group of "experts" and sorted for either extermination or to continue to live. Children slated to die were marked with a plus sign, and children who were allowed to live were marked with a minus sign. These decisions of life and death were made entirely on the basis of these questionnaires, as the panel doing the selection never examined the children. Children who were destined for extermination were transported into any one of 28 institutions which had rapidly been equipped with extermination facilities. <sup>60,63</sup>

The methods of killing included slow starvation and exposure to the cold. Some of the hospitals did not put heat into the wards where these children were kept. The doctors in these institutions boasted that they did not murder the children, but that the children simply died on their own. Other methods of killing included injections of drugs, and gassing with cyanide or other chemical agents.

The program began by exterminating children up to the age of 3 who had birth defects. By the Fall of 1941, the children's euthanasia program had been extended to include those up to the age of 17 years. By 1943, the program was broadened to include healthy Jewish children, and healthy children of other unwanted race. 63 Hitler invaded Poland on September 1, 1939, and with this assault he backdated his letter introducing "euthanasia" to the same date: "Reichschleiter Bouhler and Dr. Brandt were entrusted with the responsibility of extending the rights of specially designated physicians, such that adult patients who are judged incurable after the most thorough review of their condition which is possible, can be granted mercy killing." Following these instructions, the first questionnaires were distributed to mental hospitals. They were completed in their capacity as "experts," by Drs. Heyde, Mauz, Nitsche, Panse, Pohlisch, Reisch, C. Schneider, Villinger and Zucker, all of whom were professors of psychiatry, plus thirty-nine other doctors of medicine. Their payment was 5 pfennigs per questionnaire when more than 3,500 were processed per month, up to 10 pfennigs when there were less than 500. A cross signified death. There were 283,000 questionnaires that were processed. These experts marked at least 75,000 with a cross. 59,60

Dr. Lenz, in July 1940, expressed his views on "euthanasia" by writing: "Detailed discussion of so-called euthanasia... can easily lead to confusion about whether or not we are really dealing with a matter which affects the safeguarding

of our hereditary endowment. I should like to prevent any such discussion. For, in fact, this matter is a purely humanitarian problem." Dr. Lenz, between 1940 and 1941, suggested the following formulation for Article 2.1 of the proposed law on euthanasia; "The life of a patient, who otherwise would need lifelong care, may be ended by medical measures of which he remains unaware." <sup>59</sup>

There was scattered resistance against these early euthanasia measures, and one of the most notable was by Dr. Karsten Jasperson who was chief physician at the psychiatric hospital at Bethel. Even though Dr. Jasperson had been a Nazi party member since 1941, he instituted criminal proceedings against police groups associated with these euthanasia arrangements in the psychiatric hospital.<sup>64</sup> He also refused to fill out questionnaires, claiming that to do so was "aiding and abetting murder." Dr. Jasperson expressed his views to Martin Bormann with whom he had a long-standing tie. Bormann defended the program by contrasting the Christian view of wishing to keep alive "even those creatures least worthy of life" with the Nazi position that keeping such people alive was "completely against nature."

After the invasion of the USSR on June 22, 1941, a Special Action Group (Einsatzgruppen) was organized under the aegis of the SS, for the specific purpose of exterminating Jews, Gypsies, mental patients, and other "undesirable elements," usually by shooting. Similar groups were active on a smaller scale in Poland in 1939 to 1940. After the German armies launched their attack against the USSR, the Einsatzgruppen began their mass murders of Jews, Gypsies, mental patients and the Russians themselves.<sup>59</sup>

Heydrich was entrusted with the final solution of the Jewish question, and on October 10, 1941 he included the Gypsies as also being subject to "evacuation" (deportation to extermination camps) in a discussion about the solution of the

Jewish question.

On December 10, 1941, Himmler ordered a commission made up of those physicians who were formerly concerned with euthanasia, be set up to "comb out" prisoners in concentration camps who were unfit for work, ill, or are "psychopaths." Some tens of thousands of prisoners picked out in this way by Drs. Heyde, Nitsche and others were killed by gas in the extermination centers of Sonnenstein and Hartheim. In January 1942, the first gas chamber was built in Auschwitz, and the second in June 1942. From then on, the killings in Auschwitz were done by means of Zyklon B made by Degesch, a subsidiary of IG-Farben. It is interesting that many of these extermination camps were staffed by medical personnel who originally worked in euthanasia hospitals. An example was Dr. Mennecke, a physician involved in the euthanasia program, who wrote in a letter dated January 14, 1942: "The day before yesterday, a large contingent from our euthanasia program has moved under the leadership of Dr. Brack to the eastern battle zone . . . it consists of doctors, office personnel, and male and female nurses from Hadamar and Sonnenstein, in all, a group of 20-30 persons." This group operated the extermination site of Chelmno where Polish Jews and Gypsies were killed using carbon monoxide.59,60

On April 27, 1942, in his "Comments on the General Plan for the East," a plan formulated for the SS, Dr. Wetzel mentioned the anthropological investigation,

supported by the DFG, and conducted by Professor Abel (a department head at the Kaiser-Wilhelm Institute of Anthropology). It involved Soviet citizens in German prisoner-of-war camps: ". . .he (Abel) gave a stern warning that the Russians should not be underrated . . . in these circumstances, Abel saw only two possible solutions: either the extermination of the Russian people or a Germanization of its Nordic elements." 59

In December 1942, the research ward run by the Heidelberg psychiatrist, Dr. C. Schneider in Wiesloch became fully operational. In this ward, "idiots and epileptics" were physiologically and psychologically investigated. After being killed elsewhere, their brains were anatomically and histologically studied.

On March 9, 1943, Himmler specified in a decree that only physicians trained in anthropology should carry out the selection for killing, and supervise the killings themselves in the extermination camps. Dr. Joseph Mengele, a former assistant to Professor von Verscheur in Frankfurt, and a visiting scientist in Professor von Verschuer's Kaiser-Wilhelm Institute of Anthropology in Berlin-Dahlem, became a camp doctor in Auschwitz in May 1943. His first act was to send those Gypsies who were suspected of suffering from typhoid to the gas chambers. 59,60

#### Sterilization Laws

A committee of the Prussian State Health Council, on July 2, 1932, advised and recommended that a law on sterilization be brought in under the title: "Eugenics in the Service of Public Welfare." The law was to permit the "voluntary" sterilization of the same groups of persons (with the exception of alcoholics) as were later specified in the law of July 14, 1933.

On July 14, 1933, the first involuntary sterilization law in Germany was passed. This law provided for the prevention of progeny with hereditary defects. It allowed for compulsory sterilization in cases of "congenital mental defects, schizophrenia, manic-depressive psychosis, hereditary epilepsy, severe alcoholism, hereditary blindness and Huntington's Chorea." 65-68

On March 11, 1935, a meeting occurred with Work Group II of the Expert Advisory Council for Population and Race Policy. Drs. Fischer, Gunther, and Lenz discussed with civil servants from the Ministry of the Interior the involuntary sterilization of German colored children. In the Spring of 1937, a decision was made that all German colored children were to be involuntarily sterilized. After the prerequisite expert reports were provided by Drs. Abel, Schrade and Fischer, the sterilizations were carried out.

A scientific meeting took place from March 26-28, 1941, to mark the inauguration of the Institute for the Investigation of the Jewish Question in Frankfurt. Drs. Fisher and Gunther were guests of honor. Dr. Gross, head of the Race-Policy Bureau of the Nazi Party stated: "The definitive solution must comprise the removal of the Jews from Europe." He then demanded sterilization of quarter-Jews: "The reproduction of quarter-Jews left behind in European countries must be reduced to a minimum." <sup>59</sup>

As the war progressed, more manpower was needed for the farms and factories

and a decision was made that prisoners who were able to work should be spared extermination. However, the Nazis did not want these "undesirables" to procreate, so that fast, effective techniques for sterilization were investigated.<sup>60</sup>,<sup>67</sup>,<sup>69</sup>

On March 28, 1941, Viktor Brack, who had been placed in charge of the euthanasia program, wrote from the Reich Chancellory to the Reichsfuhrer-SS, Himmler, that the problem of sterilizing large numbers of individuals by means of x-rays had been solved in principle. The technique involved exposing the gonads of the prisoner to doses of x-radiation. In one instance, the prisoners were made to sit at a desk to register. Unbeknownst to the prisoners, their gonads were being exposed to the x-radiation. This procedure, although effective in sterilizing the individual, produced much morbidity and sloughing of tissue, and was never actively used in the sterilization program.<sup>63,67</sup>

Dr. Carl Clauberg, a respected gynecologist from Konigsberg, wrote to Himmler in June 1943 that the method which he had been developing in Auschwitz for large-scale sterilization of women is "as good as ready." "I can now see the answer to the question you put to me almost a year ago about how long it would take to sterilize 1,000 women in this way. An appropriately trained doctor could most probably sterilize several hundred, although perhaps not 1,000, in one day." The method that Dr. Clauberg developed was to inject a caustic mixture of novocaine and formalin into the woman's cervix in order to scar and obstruct her fallopian tubes. He first injected his experimental subjects with an opaque liquid in order to demonstrate by x-ray that there was no prior blockage or impairment. At his trial many of his victims testified, as did the prisoners' nurse, that many women died during or immediately after the procedure. There are also many victims who still live with terrible scarring of their tubes and uterus. 60,64,67,69

## Nazi Medical Experiments

The inhuman medical experiments conducted at the extermination camps on involuntary subjects by the Nazis are well known, and have been detailed in the Neurenberg War Crimes. The best known, and most widely publicized Nazi experiments involved the hypothermia experiments performed at the Dachau concentration camp. These experiments were designed and performed on prisoners to establish a better understanding of hypothermia and methods to gradually warm the patients, to increase survival of German fliers who were shot down in the North Sea. The controversy rages to this day as to whether this data should be used, and although the ethics go beyond the scope of this article, the authors feel that they should not, because no credence should be given to experiments of this sort. 62,67,70-75 Other experiments conducted by the Nazis on prisoners involved the evaluation of many vaccines and, particularly, the effects of Phosgene gas, which was used on a group of French prisoners.

Other experiments performed on prisoners were described in earlier sections of this paper, and included techniques for more efficient euthanasia and sterilization.

The most infamous genetic experiments were performed by Dr. Joseph

Mengele and his Jewish slave assistant, Dr. Nyiszli who sent large quantities of scientific material to the KWI of Anthropology. This material included eyes from murdered Gypsies, internal organs from murdered children, the skeletons of two murdered Jews and sera from twins infected with typhoid by Dr. Mengele. It is estimated that during his experiments, Dr. Mengele sent at least 102 pairs of eyes from twins who had been killed for these studies concerning the inheritability of eye pigment.<sup>76</sup>

## Religion

The Churches of Germany have been frequently criticized for their lack of resistance to the Nazi atrocities that were perpetrated in Germany beginning with the seizure of power by the Nazis. There were, however, many exceptions. The heroic Lutheran Pastor-Theologian, Dietrich Bonhoeffer, not only wanted to end the systematic evils of Naziism, but also wanted the nation and the Churches that had cooperated in the rise in popularity of Hitler to acknowledge their guilt. Phase Reverend Bonhoeffer was one of only a few who publicly defended the Jews after the Reichstaag passed the anti-Jewish legislation of April 7, 1933. Reverend Bonhoeffer continued his work of trying to stem the tide of Nazi cruelties, until on April 9, 1945, on order from Hitler, Bonhoeffer was hanged for his acts of treason only days before the concentration camp in which he was imprisoned was liberated by the advancing allied armies.

An effective Catholic protest against euthanasia was the famous sermon of Klemens Count von Galen, then Bishop of Munster (later Cardinal). This sermon was given on August 3, 1941, four Sundays after the highly significant pastoral letter of German Bishops had been read from every Catholic pulpit in the country; this letter reaffirmed obligations of conscience opposing the taking of "innocent" life, "even if it were to cost us our own lives." Bishop von Galen pointed out that poor, unproductive people should not lose their right to live. He stated that the danger extended not only to "invalids," who when healthy, had been hard productive workers but to "brave soldiers, who when they come back seriously wounded," were not certain of their lives.<sup>60</sup>,78

Many Germans were aroused by Bishop von Galen's sermon, and on August 24, 1941, the killing of mental patients by gas was stopped at the extermination center in Bernburg. Other extermination centers followed, although no written order exists for this directive. Two centers (Hartheim and Sonnensteim) resumed operations a few months later for concentration camp prisoners. A statistical report gives a figure of 79,723 for the number of mental patients killed, using gas, up to September 1941. This figure does not include those mental patients from Pomerania, East Prussia, and West Prussia who were shot or killed by gas. Covert euthanasia by starvation, drug, and failure to treat naturally occurring infectious disease was now introduced. A week later, the killing of Soviet prisoners of war with Zyklon B (Hydrocyanic acid) was tried for the first time in Auschwitz.<sup>59</sup>

Other religious groups participated in the resistance against the Nazi atrocities. It is interesting that for five years the Dachau concentration camp, which is northwest of Munich, was the site of the largest religious community in the

world.<sup>82</sup> Many records were hurriedly burned as American tanks approached in April 1945, so that the best estimate based on clandestine lists kept by priest prisoners in the work offices, is that 2771 clergymen were interned at Dachau, of whom at least 1034 died in the camp. The 2579 Catholic priests, lay brothers and seminarians came from 38 nations, from 134 diocese, and from 29 religious orders and congregations. Their community included 109 Protestant, 30 Orthodox and 2 Moslem clergymen.

Father O'Mally continues by stating that, "this does not include the clergy or nuns shot or beheaded, or tortured to death in squares, alleys and jails all over Europe." In the first 16 months of the war, 700 Polish priests died at the hands of the Nazis, and 3000 more were sent to concentration camps; more than half did not return. In Dachau, 868 priests perished — 300 of them in medical experiments or by torture in the prison showers. In France, by February 1944, the Gestapo had arrested 162 priests of whom 123 were shot or decapitated before even reaching any camp. The statistics also do not take into consideration the fact that there were hundreds of concentration camps in the network, and that many of the priest and clergy died in route to the various camps. 82,83

#### Anti-Semitism

In the third edition of his textbook (1931) Dr. Lenz wrote: "We must, of course, deplore the one-sided anti-Semitism of National Socialism. Unfortunately, it seems that the masses need such "anti" feelings . . . we cannot doubt that National Socialism is honestly striving for a healthier race. The question of the quality of our hereditary endowment is a hundred times more important than the dispute over capitalism or socialism, and a thousand times more important than that over the black-white-red or black-red-gold banners," (the banner of the Weimar Republic). On December 31, 1931, Himmler ordered that members of the SS must obtain permission to marry from the newly constituted Race Bureau of the SS. "Permission to marry will be granted or refused solely and exclusively on the basis of criteria of race and hereditary health." Dr. Lenz called this a "worthwhile exercise." 59,63

Hitler became Chancellor of the Reich on January 30, 1933. On April 7, 1933, the "Law for the Restoration of the Professional Civil Service" was proclaimed. In particular, it contained provisions for the dismissal of all Jewish and half-Jewish civil servants and state employees. On April 25, 1933, the Kaiser-Wilhelm Society (KWS) received a letter from the Ministry of the Interior containing directions that the law for the restoration of the professional civil service be applied to the society's employees. Two days later, the Secretary General instructed the Directors to carry out these measures.<sup>59</sup>

On July 29, 1933, Dr. Eugen Fischer recently elected as Rector of the University of Berlin, in which capacity he was responsible for signing his Jewish colleagues' dismissal notices, said in his inaugural address: "The new leadership, having only just taken over the reins of power, is deliberately and forcefully intervening in the course of history and in the life of the nation, precisely where this intervention is most urgently, more decisively, and most immediately needed.

To be sure, this need can only be perceived by those who are able to see and to think within a biological framework, but it is understood by these people to be a matter of the gravest and most weighty concern. This intervention can be characterized as a biological population policy, biological in this context, signifying the safeguarding by the state of our hereditary endowment and our race, as opposed to the unharnessed processes of heredity, selection, and elimination." In 1944, Dr. Fischer received a coveted award in recognition of his status as "The Founder of Human Genetics." Despite his obvious involvement in the Nazi racial policies, Dr. Fischer continued after the war to edit various scholarly journals and to lecture on anthropology and other topics.<sup>59</sup>

A proclamation at the Party Rally in Nuremberg on September 15, 1935, of the "law for the protection of German blood and German honor," Article 1.1: "Marriages between Jews and citizens of German or related blood are forbidden. . . ." Article 2: "Extra-marital sexual intercourse between Jews and citizens of German or related blood is forbidden." On July 31, 1941 Reichsmarschall Goering entrusted the "total solution of the Jewish question in the German sphere of influence in Europe" to Heydrich, the chief of the Security Police and the SD.<sup>59</sup>

## Interaction between American and German Eugenic Movement

Many have claimed that most Americans were unaware of the eugenic measures that were instituted in Germany during the period of Nazi rule, and were extended up to the downfall of the government in 1945. An example of the close ties which the American eugenics movement had with those in Germany occurred during the International Congress of Eugenics in Rome in September 1929, when Dr. C. B. Davenport (Cold Spring Harbor), who was President of the International Federation of Eugenic Organizations, sent Mussolini a memorandum written by Professor Fischer from Berlin on the importance of eugenics: "Maximum speed is necessary; the danger is enormous." Shortly after this, Dr. Davenport asked Professor Fischer to become chairman of the committee on racial crosses of the International Federation of Eugenic Organizations. Dr. C. B. Davenport, speaking at the International Congress of Eugenics in New York on August 23, 1932, suggested Professor Fischer as his successor as president of the International Federation of Eugenic Organizations. Professor Fischer declined because of other commitments, and Dr. Rudin (Munich) was elected.

Of particular interest are the reports from Germany from 1933 to 1941, that were printed in the foreign letter section of the Journal of the American Medical Association. During this period, these reports described the German sterilization and euthanasia programs, discrimination against Jewish physicians, reorganization of German universities, and many other topics. The German eugenic sterilization law passed on July 14, 1933 was based on a "model sterilization law" published by Dr. H. H. Laughlin in 1922.

It is interesting that on November 14, 1938, the Pittsburgh Press, in reporting on the CIO's first contitutional convention, which was held in Pittsburgh, quoted John L. Lewis as blasting a "blood-thirsty Germany" for "atrocities and

brutalities" to Jews, and promised the CIO would press the U.S. Government to come to their aid.

#### Discussion

The preceding review describes how the German euthanasia movement of the late 1930's against severely retarded and deformed children in mental institutions was expanded to include at first older children with birth defects, then healthy Jewish children and then adults who were judged as incurable or having lives not worth living. After the invasion of Poland, and particularly after the invasion of Russia, many of the teams that participated in the involuntary euthanasia programs in Germany were sent into the conquered countries, where they set up death camps that were expanded to take care of political prisoners, Jews and Gypsies, in addition to the people of the conquered countries.

It is also important to realize that the individuals who made the selections of prisoners to be killed were physicians and other health care persons. It is apparent that the physicians, themselves, believed that this was the correct approach. 60,64,67 There have been many books and innumerable articles written concerning the Nazi eugenics movement. Those that are particularly informative are: Murderous Science by a German geneticist, Dr. Benno Muller-Hill; Racial Hygiene, Medicine under the Nazis by Dr. Robert N. Proctor; Race Hygiene and National Efficiency by Dr. Sheila Faith-Weiss; and The Well-Born Science by Dr. Mark Adams. A book that should be a required reading for every medical student is The Nazi Doctors: Medical Killing and the Psychology of Genocide by Dr. Robert Jay Lifton.

## **EUGENICS: Present and Future**

It is apparent that there are some common threads as to the ultimate cause of the American and German eugenic movements. In both instances the ideas were introduced by sincere biologists and physicians who were concerned with the possible degeneration of a particular race. These ideas were made popular and more relevant by other factors. In the early 1920's in America the increasing unemployment and increasing immigration of unskilled workers made it possible for a group of dedicated eugenicists to promulgate the unfounded claim that people from Southern and Eastern Europe, Jews, Negros and Asiatics were inferior, and would dilute the Anglo-Saxon stock in the United States. This laid the groundwork for the passage of the Johnson Restrictive Immigration law of 1924. Next, these same eugenicists lobbied and convinced the various states so by 1931, 30 states had passed involuntary sterilization laws. In many instances these laws were misused so that individuals were sterilized primarily because of their race or their economic status. 37,46

In Germany, the original concerns about race hygiene in the late 19th century were expressed by scientists such as Wilhelm Schallmayer and Dr. Alfred Ploetz. By the beginning of the 20th century these concepts were beginning to be misused by those who had racist beliefs. The depression in Germany after the first World

War provided a stimulus for these beliefs to be expanded into the negative eugenics program that became one of the landmarks of the Nazi racial hygiene movement.

Many similar problems are present in the United States today. With our increasing national debt and the desire to decrease Federal and State spending, many programs that support the financially dependent population, the poor, chronically sick, and the mentally and physically retarded are in jeopardy.<sup>87-92</sup>

There has also been much discussion during the past 10 years of the concept that third party payers will cover the expenses for prenatal diagnosis, but not for the support of a child who is born with a birth defect. More of these third party payers are trying to identify individuals at risk (perhaps as an off-shoot of the human genome project or carrier screening for Cystic Fibrosis) so that they can be made to have prenatal diagnosis prior to having a child.<sup>93</sup>

With decreased Federal and State monies, increased cost of medical care and increased financial pressure on third party carriers, there are already suggestions to minimize health care at the two ends of the spectrum; namely, newborns with congenital malformations and genetic disease, and the elderly who, for some reason, are incompetent or chronically ill.<sup>87-92</sup>

Another disturbing direction is the audit of genetic services. This was recently reviewed in Great Britain.94-102 Everyone would agree that services provided for our patient's health, whether through a University or a private practitioner, should have some means of audit for quality, correct information and effectiveness. Traditionally the goal was to have the patients understand the genetic disease and their risk of having an affected child, or their chance of having a normal child. Now the suggestion has been introduced that for a genetic clinic to continue to be funded, it must show that the birth prevalence of a particular disease or malformation is declining and the termination of pregnancies for a particular disease is increasing in the population. In other words, the notion has now shifted to a cost-effective or utilitarian method regarding genetic counseling. This costeffective attitude of genetic counseling is against the present purpose of most clinics in the United States; namely, that the patient be informed and educated, and then make a decision based on his/her needs and ethical background, and not primarily because of economic measures. Utilitarian reasoning was the basis of the Nazi eugenic policies.60,66

## **Prenatal Diagnosis**

One of the first phases of the German negative eugenics movement was active euthanasia of newborns and young children with congenital malformations and mental retardation. Prenatal diagnosis and selective abortion of fetuses with malformations or genetic disease is an earlier phase of the same philosophy, namely, the elimination of lives not worth living. 85,103-105 Many centers are now developing techniques whereby the zygote resulting from in-vitro fertilization can be examined for certain genetic abnormalities. 106-112 If the zygote is found to have a chromosomal abnormality or an inborn error of metabolism, the embryo is discarded. Those who were involved in the development of prenatal diagnosis

stressed that its use was a decision to be made by the couple based on their own moral and ethical beliefs. However, as detailed earlier in this article, limited financial resources for medical care are causing more pressure for the increased use of prenatal diagnosis which represents the use of negative eugenics as part of public policy.

### **Embryo Research**

A recent editorial described how memories of the Nazi atrocities generated by the eugenics movement are causing great concerns in present day Germany, and are responsible for a much more conservative approach to embryo research than elsewhere in Europe.<sup>113</sup>

Most European countries are moving towards legislation that would permit research under strict limits, e.g., that no experiment be allowed on embryos more than 14 days old. In sharp contrast West Germany's Ministry of Justice is drafting a law that would make it a criminal offense punishable in principle by up to five years in prison for engaging in any research that would be considered harmful to a human embryo. A driving force behind the proposed legislation in Germany is a re-awakening of national sensibilities to human experimentation carried out by the Nazi doctors. Legislative proposals to minimize the potential conflict between the freedom of research and the need to respect human dignity are currently being considered in virtually every European nation. Such laws are being discussed in Britain, France, Denmark, West Germany, Switzerland, Sweden and Austria, but different countries are placing emphasis on different limits. 114-124 "The problem is not the relation of science and religion; it is which ethical principles are relevant." states S. Anderson of the Institute for Ethics at Aarhus University in Denmark. "We have utilitarian principles on the one hand, and the idea of human dignity on the other. In many European countries people are very likely to take the utilitarian starting point; but in countries like Germany, they start from human dignity as a first principle."113,124

## **Newborn Screening**

Although most of us applaud the screening of newborns for treatable genetic diseases, to prevent serious physical and mental retardation, it is not without some risk. 125-127 Most of these diseases are autosomal recessive, so that when parents have a child with, for example, PKU, Sickle cell anemia or cystic fibrosis, they are known to be obligate carriers of this mutant gene. Although the parents are not affected, with each subsequent pregnancy there is a one in four risk that the child will be affected. Third party payers are now considering the possibilities of encouraging these parents to have prenatal diagnosis and to abort affected children. If they fail to do so, the affected child will not be covered by their health insurance.

In the past there has been a lack of counseling after newborn screening so that many parents did not know the difference between their child being a normal carrier and being affected. For example, after sickle cell screening, carriers were stigmatized as being undesirable marriage partners or were socially ostracized. In New York State, there was confusion between the disease and the carrier state, which led to insurance companies denying sickle cell carriers health and life insurance.

## Population Screening for Carriers of Cystic Fibrosis

Cystic Fibrosis (CF) is the most common serious genetic disease in the Caucasian population. With new molecular genetic techniques, the gene has been located <sup>128-130</sup> and it is possible to identify many carriers of CF, and some health professionals have advocated screening the entire population. At this time, it is not feasible since only 70% of the American Caucasians carry the common deletion, namely Delta F 508. <sup>131</sup> Other mutations have now been identified and screening can be more effective. Once mass screening has started, we have the ongoing question of who should receive this information, namely, third party payers, life insurance companies, the employers, spouses or other relatives. Most believe that this is information that only the patient should have. <sup>132,133</sup>

## The U.S. Human Genome Project

The U.S. Human Genome Project is the largest scientific project funded by the Federal Government since the Apollo Moon Project. 134-136 The knowledge gained from this project should have tremendous implications, not only to physicians, but to everyone, lay and professional, by providing a better understanding of single gene defects and the common multifactorial or familial diseases such as diabetes, arteriosclerosis and cancer.

The initial phase of the human genome project will be directed at developing new skills and technologies to enable researchers to map and sequence all three billion base pairs that make up the human genome. This will yield knowledge of the entire DNA contained in a human being; not only the genes themselves, but also the genetic material between these genes that has been, until now, relatively unknown. 137,138 The cost of this project was initially estimated to be about \$3 billion, but it is now expected to exceed this. The fund will be spread over 15 years.

The ultimate goal will be to provide information to help understand and ultimately treat genetic disease. At first, single gene disorders will be explored, but as more information accumulates, so called multifactorial diseases (diabetes mellitus, hypertension, some forms of cancer) will be better understood and hopefully treated. In 1986 Arnato Delbecco indicated that by sequencing the Human Genome, the answer to many fundamental problems of cancer would be available. As scientists discuss the organization and priorities of mapping the human genome, others are discussing the possible use and misuse of the information generated by the project.

Plans to further integrate European research efforts into the mapping and sequencing of the human genome are being given a rough ride by the European Parliament.<sup>124</sup>,<sup>139</sup> In January 1989, a parliamentary committee proposed that the program should include substantial support for the studies of social and ethical

implications of such research. Commission officials say that the so-called Predictive Medicine Program will pay careful attention to the social and ethical aspects of the research. But its top priority is to "develop scientific and technological underpinnings" for the research. However, critics in the European Parliament, the elected body that has an important role in influencing the commission's activities, are arguing that the priorities should be adjusted, if not reversed. They believe that satisfactory answers should be found for some of the questions raised by the research before it is allowed to proceed. A leading critic, Benedikt Haerlin, a parliamentary representative of a group linked with the German Greens stated, "We are playing with the very substance of humankind and human dignity. It is crucial to have a proper understanding at this stage of the hazards which may be involved and not be too euphoric about the research." Reflecting these views, the Energy, Research and Technology Committee of the Parliament added substantial amendments, many written by Haerlin, to the Commission's proposed program. The amendments stipulate that the program be broadened to include funding, for example, for a study of "The History of and Current Trends in Eugenics" and for the "preparation of a list of possible and measurable measures to prevent the misuse of scientific knowledge of the human genome." More specifically, the committee is proposing that "clear legal agreements be concluded with individuals whose DNA is studied, covering the "nature of the use and study of their DNA and the rights of those concerned with respect to the use of the research results."124

A continuing concern of the United States Human Genome Project is the question of the right of privacy of each individual whose genome is sequenced. 140-142 Everyone has a unique sequence of DNA that can serve as a fingerprint. DNA fingerprinting is now a routine test that can be done in paternity tests and in forensic cases. This is performed on a patient to laboratory basis. The concern is how should a person's entire genome be used and what is the degree of privacy that should be allowed? For example, if it is found that a certain genetic sequence is associated with increased or decreased IQ, or to a predilection to a serious disease, should this information be made available to companies that sell life insurance, health insurance or to that patient's employer? Should an individual's genomic information be available to his/her spouse and other family members if it contains information that might be relative to them?<sup>143</sup> Another issue is the use of discarded tissues for DNA sequencing without the individual's knowledge or permission. Examples might be the blood spots that are obtained for newborn screening. Should this information be obtained without the patient's expressed consent? Who should have access to the information once it is obtained?

More specifically related to eugenics, we have seen that in the past, various racial characteristics have been used in formulating eugenic policies, both negative and positive. If it is found that certain genomic sequences can be used to predict physical or intellectual fitness in an individual, will this become the issue of the 21st century when government or third party payer policies are being implemented?

## Maternal Serum Alpha Fetoprotein —

## Maternal Serum Human Chorionic Gonadotropin (MSAFP - HCG) Testing

This is a screening procedure by which the status of the fetus is determined by evaluating high or low levels of these compounds. Since the early 1970's MSAFP has been used as a screening tool to determine the risk for the fetus having an open neural tube defect or some other congenital malformation. He for approximately the last five years low values have also been evaluated to determine the risk of the mother carrying a fetus with Down syndrome. He has been found by many investigators that by adding HCG to the calculations, the risk can be even better defined. With these values, even though they are elevated or low, the baby is usually found to be quite normal. However, after evaluating the fetus by specific diagnostic tests, if birth defects are found, the babies are frequently aborted. Another example of negative eugenics which is accepted public policy and paid for by most third party payers.

#### Chronic Alcoholism

As described earlier in both the American and German eugenics movements, chronic alcoholics were listed as candidates for involuntary sterilization, and in the German eugenics movement, in many cases, euthanasia. There is some evidence that there is a genetic component to alcoholism. A recent study indicated that the D2/Taq1 allele (A1) for the dopa receptor gene might be involved in increasing susceptability to chronic alcoholism. However, shortly after this study was published, another study showed no consistent association between the D2 receptor gene and a predilection to chronic alcoholism. If further studies on the A1 allele or on another marker show a correlation between alcoholism, it could indicate a person who has an increased risk of becoming an alcoholic. This could be used in a discriminatory way to keep these people from obtaining health and life insurance or from working in sensitive areas. This is a violation of that individual's privacy.

#### Conclusions

It is sometimes difficult to reflect objectively concerning our actions and practices. Particularly, how new advances in science and technology and their applications to genetic counseling and clinical care in medical genetics can possibly be deleterious to our patients. In the past, however, we have seen how rather innocuous medical practices or public policies have been distorted to be applied as negative eugenics abrogating the rights and privacy of millions of individuals. Is a painful to realize how some of our accepted practices today (for example, prenatal diagnosis and MSAFP/HCG screening) can be considered as negative eugenics. However, when these technologies were introduced into medical practice, it was on the basis of a patient/physician relationship. Now it is becoming public policy where the individual patients are losing, in many instances, their right to make a decision. This might not be their choice, but one

dictated by the subtle influences of economic pressures and the increasing reliance on utilitarian cost-effective criteria for making genetic decisions. 153

These technologies will increase in scope and effectiveness with each subsequent year. It is important as health care providers that we realize the necessity of protecting our patients' right to make their own decisions, and to protect the confidentiality of their genetic records in the work place, in relation to third-party carriers, the government and other individuals. Human life must be respected and those with birth defects and genetic disease are protected by providing support with care and educational opportunities. A monumental step in this direction was the signing into law by President Bush on July 26, 1990 of the "Americans with Disabilities Act." This new law will help an estimated 43 million Americans with disabilities and has the force of a national law.

There is also the question of legality. We know that Hitler legally killed millions of individuals aided by physicians who believed in his philosophy. The sterilization laws that were passed in this country harmed thousands of innocent people who expected the law to protect them. 153 As physicians it is of the utmost importance that we live by the Hippocratic Oath and not be deceived again by legal terminology. The Constitution protects us only when it is interpreted correctly.

In closing we would like to quote a Protestant Theologian, Dr. Karl Barth: "No community whether family, village or state is really strong if it will not carry its weak and even its very weakest members. They belong to it no less than the strong, and the quiet work of their maintenance and care, which might seem useless on a superficial view, is perhaps more effective than common labor, culture or historical conflict in knitting it closely and securely together. On the other hand, a community which regards and treats its weak members as a hindrance, and even proceeds to their extermination, is on the verge of collapse." 154

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