

CMDA Ethics Statement

Use of Genetic Information and Technology

As Christian physicians and dentists we affirm:

- All human beings have been individually created through the providential interest and design of Almighty God. Being created in the image of God, every human being has infinite worth, regardless of genotype or phenotype.
- The diversity of individuals is part of the wonder and strength of God's sovereign design.
- Each human life is a composite of genetic, environmental, social, volitional and spiritual factors.
- God has endowed humans with minds capable of exploring but only partially understanding the magnificence and intricacies of His Creation. Human knowledge and wisdom are limited and may be used for evil or good.
- God has mandated good stewardship of Creation, both of ourselves and the surrounding world.

Therefore, we believe:

- The presence of a disability, either inherited or acquired, does not detract from a person's intrinsic worth.
- The scientific exploration of life, including its genetic foundation, is proper and consistent with God's mandate and humanity's created nature, but must be conducted within biblical constraints.
- Genetic information may be of legitimate value in guiding the care of patients.
- Because a minor is unable to give informed consent, for genetic testing of a minor to be performed, it should benefit him during the period of time prior to majority. Therefore, pre-symptomatic testing of a minor should not be performed for disorders that will not either affect his health until after majority or result in therapeutic intervention before majority.
- An individual's genetic information should be kept strictly confidential.
- Somatic cell manipulation to replace absent or defective genes is consistent with the goals of medicine, and may be good stewardship of knowledge. Such manipulation should be performed only after extensive study demonstrates the specificity, benefits and risks of these interventions, or as part of an approved clinical trial.
- Germ cell manipulation as a technology carries with it a much higher risk of harm and abuse than somatic cell manipulation, in that it affects future generations. But, we do

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not believe it is appropriate to preclude categorically the potential use of this technology. It may become possible to correct safely and specifically some severe deficiencies (e.g. hemophilia) for multiple generations, and we do not wish to condemn such a beneficial use of technology.

We oppose:

- The search for and use of genetic information to justify destroying an existing life, born or unborn.
- The use of genetic information for discriminatory purposes including infringement upon the right to procreate.
- The use of genetic manipulation to augment human attributes.
- The use of a patient's genetic information for societal benefit if such use harms or could potentially harm that individual.
- The reductionist belief that humans are simply the product of their genetic destiny.

As more knowledge becomes available, we need to seek humbly and prayerfully God's wisdom and guidance in the use of genetic information and technology.

*Approved by the 1996 House of Delegates
Passed with 78 approvals, 2 opposed.*

HISTORICAL PERSPECTIVE*

The word, eugenics, was coined in 1883 by Charles Darwin's cousin, Francis Galton, a biologist and Social Darwinist who used statistical correlations to study the inheritance of intelligence. The term was built out of the Greek *Eu* (good) and *Genics* (in birth). Galton's aim was to improve human stock by gaining knowledge and instituting public policies that would help "the more suitable races" prevail over "the less suitable races" in order to maximize intelligence and to prevent feeble-mindedness. He advocated scientific marital arrangements to breed intelligent children.

The practice of eugenics, quite apart from the existence of the word, has existed from ancient times and it has always been associated with death – with defining and eliminating the unfit. In the ancient world it involved exposing infants. In Greece (both Plato and Aristotle supported the practice), in Sparta, and in Rome under the Laws of the Twelve Tables infants were exposed in order to eliminate visibly impaired newborns and to weed out the weak. In the Middle Ages law, medicine, and religion, largely under the influence of Judeo-Christian teaching, condemned euthanasia, and it was seldom practiced. The exception was monsters or "changelings" believed to be imps left behind by demons who had stolen the "real" baby. These were not considered to be human beings; thus exposing and killing them did not violate the ban on infanticide (a view endorsed by Martin Luther himself). Beginning about 1870 a few physicians and others began to publicly advocate not nurturing or actually killing defective persons or defective newborns.

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On November 12, 1915, a now largely forgotten but then famous case catapulted eugenics into the public eye. In Chicago's German-American Hospital a severely deformed baby boy was born to the Bollinger family. The surgeon who headed the hospital staff, Dr. Harry J. Haiselden, convinced the mother not to treat the child, but to let it die. Haiselden revealed that he had let a number of "defectives" die during the preceding decade, and that he would continue to do so. All this was widely reported by the newspapers. His decision was backed by public figures such as Clarence Darrow and Helen Keller. The courts did not indict him; neither did the media. Subsequently he wrote and starred in a movie concerning this incident. In the movie, entitled "The Black Stork," Haiselden advocated the protection of society from "defectives." It was a kind of morality play based on the dangers of allowing mentally or physically defective children live because of the likely possibility that they might become criminals. The movie was shown in theaters from 1916 to 1920. After 1918 it appeared under the title *Are You Fit to Marry?* It was revised and re-released in 1927. It continued to be shown in small theaters and traveling road shows until perhaps as late as 1942.

During the early 20th Century partly due to the famous case portrayed in "The Black Stork" and partly due to other "eugenic movies" of the time, the eugenics movement made enormous gains in public approval and support in the United States. It was endorsed by the national media, practiced by medical science, given carte blanche by the courts, and defended by the leading intellectuals of the day.

Initially the eugenics movement believed the defective person was unfit to reproduce but should not be killed. Segregation or sterilization of the unfit became the answer. The hope was that medicine or surgery (even or tonsillectomy or adenoidectomy!) could effect cure. Then "allowing to die" or "twilight sleep" (deep and continuous sedation) was advanced as a humanitarian way to eliminate defectives. Finally killing (in the form of abortion) was advocated to save the parents from suffering. As Helen Keller put it, "Our puny sentimentalism has caused us to forget that a human life is sacred only when it may be of some use to itself and to the world." Doctor Haiselden insisted that he let defectives die "because he loved them." He emphasized the need to protect society from what he termed "lives of no value." He maintained that "by the weeding out of our undesirables, we decrease their burden and ours." Clarence Darrow said we should: "Chloroform unfit children. Show them the same mercy that is shown beasts that are no longer fit to live." Haiselden warned that: "Cold hard logic...cannot be overturned by false and sickly sentiment."

Medicine at this time began to develop an enormous power (the expert) over all of life. The *New York Times* strongly urged that non-treatment decisions should be "kept strictly within professional circles, without the horrified exclamations of unenlightened senti-mentality." Helen Keller called for "physicians' juries for defective babies." A Chicago realtor called for "legislation creating a commission authorized to put to death painlessly hopelessly imbecile children," though he thought it "desirable to obtain the consent of parents."

The leading intellectuals believed that scientific methods provided an objectively true basis for both emotions and ethics, far superior to those false sentiments whose only basis was irrational social conventions. Allowing baby Bollinger to die was not a victory of cold logic over love, Haiselden insisted, but a victory of objective love over sentimental love. "Kindness took the highest form," triumphing over "false sentiment, false man-hood, false humanity," he proclaimed. The Philadelphia Ledger called his decision "the highest benefaction."

The practice of eugenics took two directions: 1) Negative Eugenics. Eugenics became closely associated in Europe and the United States with segregation, forced sterilization of the "unfit," and decisions by doctors and / or parents to allow deformed or defective children to die. "Unfit"

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was a term aimed against the Black race, immigrants, the poor, the immoral, criminals and the mentally defective. The United States was an early leader in the sterilization movement. By the year 1920 twenty states (beginning with Indiana) had forced sterilization laws, and between 1931 and 1939 over 20,000 institutionalized patients were sterilized. These laws had the support of medicine, the media, and the courts. *Buck v. Bell* was a famous case in 1927 in which the Supreme Court upheld the constitutionality of Virginia's involuntary sterilization program. In the words of Justice Oliver Wendell Holmes, Jr., who wrote the majority decision: "Three generations of imbeciles is enough." Another famous case was the 1936 suit of Ann Cooper Hewitt against her mother and two doctors for sterilizing her without her knowledge or consent during an emergency appendectomy.

2) Positive Eugenics. Beginning in the 1920's world leaders became concerned that the middle and upper classes were not having children at the same rate as the lower classes. Much effort was made to induce the "fit" (meaning the white middle class) to have children. Advocates of the worldwide Birth Control League, later to be called Planned Parenthood Federation of America, advocated "more children for the fit, less from the unfit – this is the chief issue of birth control." Eugenics research in the U.S. was done at Cold Spring Harbor, New York, led by Charles B. Davenport and funded by the Carnegie Institution in Washington and by Mary Harriman.

In Germany eugenics was at first called racial hygiene (*Rassenhygiene*) – a term coined by the German Social Darwinist, Alfred Ploetz, in writing the movement's founding document. The Nazi project was a vision of absolute control over the evolutionary process, over the biological human future – a kind of "biocracy." Rudolf Hess asserted that "National Socialism is nothing but applied biology."

In the late 1930's the Nazi government directly joined eugenics to euthanasia. The latter activity began with the killing of the non-rehabilitatable sick or defective and ended with the destruction of anyone (specifically Jews, Gypsies, and Slavs) defined as inferior (life unworthy of life = *leben unwürdiges lebens*). The crucial work justifying this decision – "The permission to Destroy Life Unworthy of Life" – was published in 1920 and written jointly by two distinguished German professors: the jurist Karl Binding and the physician Alfred Hoche, professor of psychiatry at the University of Freiburg. The latter coined the term, "life unworthy of life." Their plan was to have a three-man panel (a physician, a psychiatrist, and a lawyer) to decide upon request regarding the permissibility or advisability of euthanasia. The request that someone be killed could be withdrawn at any time.

In early October 1939 – a month after World War II had begun – Hitler issued orders that certain doctors be commissioned to grant "a mercy death (*Gnadentod*) to patients judged incurably sick by medical examination." The camouflage organization created for the medical killing was the Reich Work Group of Sanatoriums and Nursing Homes operating from the Berlin Chancellery at its Tiergarten 4 address – hence, the overall code name "T4" for the project. The transportation service created for this function was ironically called the Common Welfare Ambulance Service Ltd. There is evidence that although a specific order for the Final Solution (*Endlösung*) was issued by Göring to Heydrich on 31 July 1941, it was actually requested by Heydrich and drafted by Eichmann.

The German medical profession aided and abetted this effort. As many as 50% of German physicians joined the Nazi party and many participated in the genetic and other medical research projects in the concentration camps. The medical experimentation on prisoners in the German concentration camp system, so egregiously exemplified by the twin-studies of Dr. Mengele at Auschwitz, was justified on utilitarian grounds as making use of human material that was going

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to be destroyed anyway. These acts were later judged to be criminal in the Nuremberg trials. From those trials came the modern guidelines for informed consent.

Beginning in the 1940's and extending into the 1950's, largely because of the events in Nazi Germany, the term, eugenics, was avoided, forced sterilization was abandoned, and the practice of categorizing people as unfit was viewed as class bias. But beginning in the mid-1950's efforts to improve the race reappeared. Positive Eugenics was promoted in the form of encouragement to breed from "superior" stock (e.g. from a sperm bank storing sperm produced by scientists). Negative Eugenics began to be endorsed by centers for genetic counseling.

Today eugenics is newly associated with the voluntary and the autonomous, but it is also, as before, allied with the destruction of innocent human life. Its destructive practices once again have the support of medical science, the media and the courts. In addition eugenics is now supported by a growing and increasingly profitable technological industry.

Positive eugenics now involves prenatal genetic testing, in vitro screening of gametes and zygotes, and prenatal testing with the prospect of using technology to eliminate the carriers of undesirable genes or (theoretically) to add desirable genes. There exists the future prospect of producing "superior" babies.

Negative eugenics exists in the practice of destroying unwanted or defective human life identified by in vitro pre-implantation genetic screening or *in utero* prenatal genetic testing. The issues involved are hidden by such euphemisms as "freedom of choice" or "the right to privacy" or "eliminating or preventing suffering." These terms really mean the destruction of the prospectively defective child. Much pressure is brought by our society against any decision to give birth to a defective child, and the worth of such a child is impugned (as before) on purely utilitarian grounds. More recently liability for "wrongful birth" of a defective baby or for an adverse outcome in delivery (often subjectively de-fined as an "imperfect" baby) has become a substantial threat to medical caregivers.

These societal attitudes are in conflict with our traditional Judeo-Christian religious beliefs that all human life bears the image of God and therefore is sacred and inviolable. They ignore the teachings of our national founding documents which assert and make provision for the idea that all men are created equal and are endowed by their creator with certain inalienable rights, including life. And they violate even the secular philosophical principle that no human life may be used as a means to an end. Our society is degraded when it legitimates the destruction of innocent human life and unconsented to control or use of others.

The eugenics agenda of our society today is in many respects not different in principle from the eugenics agenda of the Western Civilizations of the late 19th and early 20th centuries. Its practices are accompanied by death, justified by science, motivated by the desire to produce superior humans, and made palatable by obscuring euphemisms. The horror of doing evil in the name of good will continue unless we exercise clarity of moral thought and develop ethical boundaries and guidelines for eugenics. Those who would foresee the future of medicine without moral guidelines will do well to look at the history of Eugenics

*This perspective on the history of eugenics has largely followed the thought of Arthur J. Dyck, Ph.D., in "Eugenics in Historical and Ethical Perspective", GENETIC ETHICS, Do The Ends Justify The Genes?, edited by John F. Kilner, Rebecca D. Pentz, and Frank E. Young (Eerdmans Publishing Company, Grand Rapids, Michigan, 1997)

The narrative is supplemented by information from:

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6. THE BLACK STORK, Eugenics And The Death Of “Defective” Babies In American Medicine And Motion Pictures Since 1915, Martin S. Pernick, (Oxford University Press, New York, Oxford, 1996)