The right to life: Who is to decide?

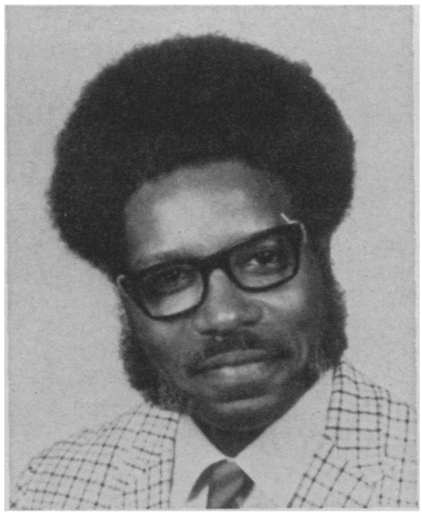
Intrauterine diagnosis of an increasing number of genetic diseases is forcing decisions on which fetuses, if any, should be aborted. Eugenics is under way introducing some agonizing questions

by Joan Lynn Arehart

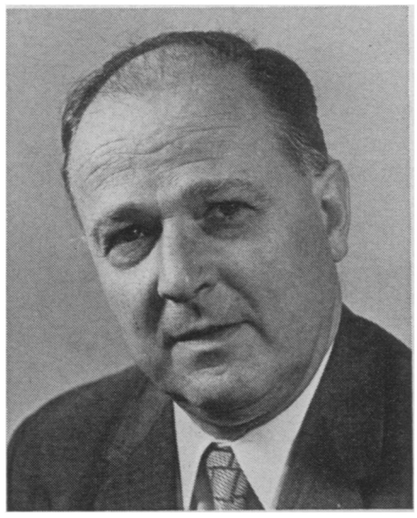
The breakdown in the traditional physician-patient relationship in recent years has precipitated an avalanche of malpractice suits that call the basic ethics of clinical practice onto the stand. When does medical judgment become negligence? Must patient consent always be obtained before treatment is applied? How much does a patient have a "right to know" when the prognosis is negative? Must the physician always regard communication with a patient as privileged?

But the current revolution in medical ethics goes far beyond just the doctor-patient relationship. It stems from recent advances in basic medical research, such as organ transplants, prolonging the life of terminal patients, prenatal diagnosis of genetic diseases and artificial insemination. To confront such questions and try to find intelligent ways of dealing with them, various groups have sprung up in the last year or so. One of the largest and most active is the Institute of Society, Ethics and Life Sciences in Hastings-on-Hudson, N.Y. (the Hastings Center).

From Oct. 11 through 14 the Hastings Center, in conjunction with the National Institutes of Health, brought together some 85 scientists, philosophers, lawyers and theologians in Warrenton, Va., to tackle ethical questions raised by genetic counseling or screening and prenatal diagnosis of chromosome abnormalities and genetic diseases. Genetic screening and prenatal diagnosis are being sought by an increasing number of couples. The listing of chromosome abnormalities and genetic diseases that can be diagnosed from fetal cells withdrawn by amniocentesis (from the mother's abdomen) expands



Murray: Opposes mass screening.



Ulli Steltzer

Ramsey: Raises some moral questions.

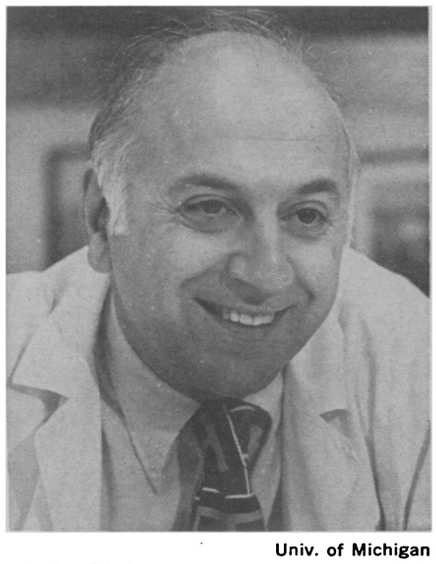
monthly. And life and death sentences are being passed on "defective" fetuses every week. The number of abortions of defective fetuses in the United States, one scientist estimates, now stands at between 200 and 500 a year. Although the conference did not produce easy answers to the questions posed, it provided a climate for communication among various disciplines.

Genetic counseling and prenatal diagnosis allow many couples to have children they might otherwise not risk. But some persons, such as Robert Murray Jr., a physician at Howard University, oppose mass screening for any disease, such as sickle cell anemia, where the options are essentially negative: "Don't marry another carrier," or "If you do, don't have children." Prenatal diagnosis is also essentially negative for now because the only therapeutic recourse open to parents of a fetus diagnosed as defective is abortion. For this reason other conference scientists advise against large-scale application of the technique.

Selectively aborting "defective" fetuses also raises the question of what life is, and who has the right to life. Harold Himsworth, until recently secretary of the British Medical Research Council and ethical adviser on such controversial scientific endeavors as nuclear radiation and the use of fetuses in research, defines "being alive" as an organism's ability to function as an integrated whole. But the concern here, he cautions, is with "becoming alive." In mammals there are stages of becoming alive, and physiologically speaking there is a scale against which aliveness can be measured. The hub of the prob-

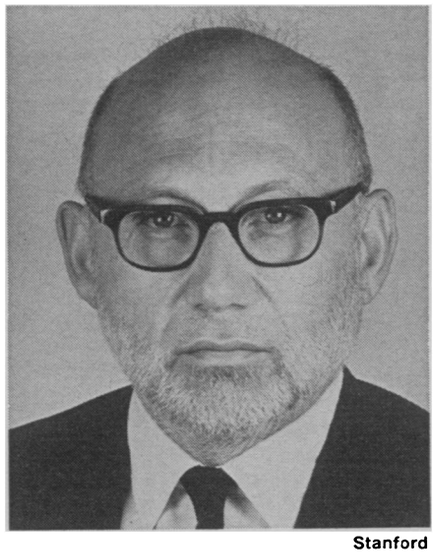
lem then, Himsworth concludes, is at what stage does a fetus become a human? None of the scientists at the conference ventured an answer.

Even the most irreligious mother is faced with cosmic doubt if not downright anguish after aborting a fetus that has been diagnosed as defective, says John Fletcher, minister at the Metropolitan Ecumenical Training Center in Washington. John Littlefield of the Massachusetts General Hospital points out that one in every six couples with a child diagnosed before birth as defective decides to go ahead and have it. As prenatal diagnosis of genetic diseases becomes increasingly common, he asks, might those parents who decide to bear a child diagnosed as defective be penalized by, say, health insurance companies or other strictures? Looking even further into the future, Leon Kass of the Committee on Life Sciences and Social Policy of the National Academy of Sciences asks: Might defective children who escape abortion become marked by society?



Univ. of Michigan

Neel: Little impact on gene pool.



Stanford

Lederberg: Work to correct defects.

Kass came out against abortion on any grounds, genetic or otherwise, as did Jerome LeJeune, professor of genetics at the University of Paris—in spite of strong opposition from some other scientists present. Paul Ramsey, professor of religion at Princeton University, was scored by some scientists, particularly by Michael Kayback of Johns Hopkins University, for suggesting that mass application of prenatal diagnosis might be morally questionable because physicians, in their zeal to uncover defects, might abort a few perfect fetuses by mistake. Kayback was especially defensive because he has screened some 10,000 couples in the past several months for carrying the gene for Tay-Sachs disease (which causes severe mental retardation and brings death to an infant within the first several years of life) and has diagnosed 40 fetuses suspected of having the disease. Of these 40, 31 were diagnosed as normal and were born normal. Of the nine diagnosed as afflicted with Tay-Sachs, eight were aborted and found to indeed have the disease. The one fetus diagnosed with the disease and carried to term also had the disease. However someone pointed to other evidence that since mass screening for PKU (phenylketonuria, a genetic disease causing severe mental retardation) has become prevalent for newborns, some infants have been mistakenly diagnosed as having the disease.

James V. Neel, a geneticist at the University of Michigan, countered the fear expressed by several minority spokesmen present that aborting fetuses having, say, Tay-Sachs (to which Eastern European Jews are especially vulnerable) or sickle cell anemia (which mostly strikes blacks) might in the wrong hands be wielded for large-scale ethnic or racial genocide. There is small chance that aborting fetuses for genetic defects would have much of an impact on the gene pool of a particular population, Neel said.

Legal dilemmas are being raised by genetic counseling and prenatal diagnosis as well. Must the physician, as genetic counselor, divulge all information obtained from familial studies and laboratory tests to the client? Full disclosure is not required under the traditional, paternalistic doctor-patient relationship. Another question is whether a counselor who looks into the genetic makeup of family members of persons seeking counseling is invading their privacy. Of the vast number of malpractice suits filed to date, only several have concerned experiments and none so far have dealt with genetic counseling or prenatal diagnosis, according to Alex Capron, a lawyer at Yale University. Yet Harold Green, a lawyer at George Washington University, is convinced that such suits will eventually come, and judges will not look for precedents in common law but rather examine each case on an individual basis.

Following the Hastings-NIH conclave was the all-day medical ethics symposium in Washington sponsored by the Joseph P. Kennedy Jr. Foundation (SN: 10/23/71, p. 275). In spite of the tendency for Kennedy Foundation medical happenings to reinforce Kennedy family views on, say, abortion (participants are carefully selected and sometimes prompted, according to several heroes and heavies in both this and past Kennedy dramas), the Oct. 16 forum allowed ample free interchange on the subject of the right to life as raised by prenatal diagnosis of birth defects. Joshua Lederberg, a Stanford University geneticist, pointed out, as Himsworth had done at the Hastings-NIH conference, that the basic question is when a fetus becomes human. Most biologists, Lederberg says, accept "becoming human" sometime between conception and birth, but are reluctant to go further at this time. LeJeune, also a participant at the Hastings conclave, said that "being human" is actually "becoming human," and that no human is ever finished. LeJeune would arbitrarily set the "human arrival" point at about seven years of age.

Yet, even if one decides when a fetus becomes human, there is the thorny question of what constitutes a genetically sound person. Every American carries at least 5 to 10 defective genes, according to Kayback, another alumnus of the Hastings conference. Lederberg admitted that being a Nobel laureate, as he is, assures even him no passport into the realm of normalcy. In fact, most panelists present uncomfortably agreed that had a treatment not been found for PKU babies several years ago, PKU victims might today be included on the defective fetus-abort list. Carried to its logical conclusion, some participants prophesized, there is reason to believe that all human "defectives," Rh negatives and left-handers alike, might eventually be defined out of the human chromosome lottery.

And assuming a fetus has rights. whether normal or defective, the question is how those rights stack up against those of the parents or of society. There were few things all the panelists agreed on, but one of them was that individual rights should preempt some larger "social good." However there was staunch disagreement over whether the fetus' rights equal those of its parents. Daniel Callahan, director of the Hastings Center, favored the parents. Kayback pitted the fetus against the parents.

Although few practical courses were mapped at either the Hastings or Ken-

nedy conferences on these questions, Lederberg did offer a suggestion: "Let's stop torturing ourselves and perform the research necessary to correct fetal defects in utero. By really putting our shoulders to it, we can eliminate many of the ethical problems we are now facing." Unfortunately little evidence was presented at either the Hastings or Kennedy conclaves that scientists are exerting large efforts to provide defective fetuses with, say, drug or enzyme therapy via the amniotic fluid.

Yet even if, and when, fetal medicine becomes available, the more profound implications of the ethical questions raised by genetic counseling and prenatal diagnosis aren't liable to be dissipated. "Behind the horror at genetic defects," Callahan said at the Hastings conference, "lurks an image of the perfect human being"—as opposed to several other human ideals such as human individuality and diversity. Now that medical research has given man the power to play God, he isn't sure what to do with it; for once he starts, where does he stop? Said Robert Sinsheimer of the California Institute of Technology at the Hastings conclave, "Nature has no absolutes—only man, in his incompetence." Several scientists at that meeting suggested that there might be some things man would be better off not knowing, not achieving. Yet not one scientist present at either the Hastings or Kennedy meetings offered to turn in his or her electron microscope.

And as both conferences bore out, such nettling ethical questions are just arising with genetic counseling and prenatal diagnosis. In an interview at the Hastings meeting, for example, Cecil Jacobson, an obstetrician-geneticist at George Washington University Medical School, said that when he artificially inseminates patients he tries to use semen from men who have at least 12 years of education. Applying such a criterion might be considered a mild brand of eugenics, Jacobson admitted, "if education is any criterion of intelligence." Then expectations were voiced at the Hastings conclave that artificial inovulation of women might be accomplished within a year, as well as cloning of the first mammal (only amphibians so far). However scientists at that meeting tend to concur with microsurgeons close to the scene (SN: 9/4/71, p. 152) that embryonic gene engineering is a way off yet—and in spite of recent unprecedented success in using a virus to correct for a defective human gene in tissue culture (SN: 10/23/71, p. 276). If this is truly the case, it will give medical ethicists more lead time (between scientific achievement and widespread clinical application) to decide what to do about the double strand of human DNA which, against all odds makes humans what they are. □

Magnetic reversals and biological extinctions

An increase in cosmic-ray dosage when magnetic fields weaken is often proposed as the cause of extinctions, but there is now evidence of direct harmful effects of reduced magnetism on organisms

by Louise Purrett

A number of times throughout history life on this planet has been seriously and inexplicably disrupted. The fossil record of life on earth shows massive, sudden extinctions of marine species about 500 million and 250 million years ago and less serious periods of extinctions at the end of the Ordovician, Devonian, Triassic and Cretaceous periods (425 million, 345 million, 180 million and 65 million years ago, respectively).

The cause of these extinctions is one of the major unsolved mysteries of the earth sciences, but in many cases they appear to have some relation to magnetic reversals. James D. Hays of Columbia University's Lamont-Doherty Geological Observatory reports, for example, that during the last 2.5 million years eight species of radiolaria (microscopic marine animals) became extinct and six of these extinctions occurred directly after a magnetic reversal (SN: 11/21/70, p. 392).

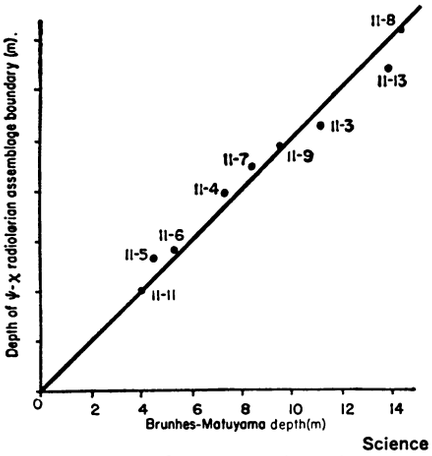
In 1963, Robert J. Uffen of the University of Western Ontario suggested that there may have been a causal relation between magnetic reversals and the extinctions. How magnetic reversals might affect terrestrial life has not been settled, however. During a reversal (SN: 4/10/71, p. 251) the magnetic field's intensity diminishes to zero and then builds up again. While the magnetic intensity is low, cosmic radiation that it normally shields out is allowed to bathe the earth's surface. This radiation, Uffen proposed, would have produced mutation rates many times greater than normal and thus be "a major influence in evolution in the presence of the environmental selection pressures of those times."

There were a number of problems with this theory, however. C. J. Waddington of the University of Minnesota demonstrated in 1967 that the increased radiation dosages experienced at sea level as a result of removal of the magnetic field's shielding effect would be too small to have a significant effect on population levels.

The thickness of the atmosphere, he says, would render cosmic radiation entering between the equator and polar regions relatively inefficient in producing sea-level cosmic-ray dosage. Further, some of the changes in radiolaria populations occurred in Antarctica. Because of the shape of the magnetic field, the poles are not shielded from radiation even when the field's intensity is at its peak, so that a magnetic reversal would produce almost no increase in radiation dosage.

The summary effect of removing the field, he says, is to increase the radiation dosage due to cosmic radiation by no more than six millirads (a measure of absorbed dosage) per year and to increase that taken up by organisms by no more than two millirads per year. "These values are so small, particularly in comparison with the general background radiation levels always present, that it seems inconceivable that they could appreciably affect the evolution of any organisms."

Finally, says Ian K. Crain of the Australian National University, the radiation hypothesis fails to explain how marine life, which is shielded from cosmic radiation by the sea water, can be affected by increases in radiation in the atmosphere.



A polarity change and radiolarian extinction: Strong correlation.