

# Questioning the New Genetics

The man stood up and flatly asserted, with the cool of a Boston Brahmin, that those of us with genetically defective pedigrees do not have a right to reproduce. "The right to reproduce is a privilege," he declared. "Our gonads and gametes are not private possessions."

The speaker was not someone out of Aldous Huxley's *Brave New World*, and he was not a Hitlerian eugenicist exhorting a Nazi rally. He was Joseph Fletcher — a Massachusetts moral philosopher, now with the University of Virginia — addressing a potpourri of M.D.s, Ph.D.s, lawyers, genetic counselors, rabbis, priests, fellow moral philosophers and concerned citizens at the second National Symposium on Law and Genetics, held recently in Boston. And as might be expected, audience members with less-than-perfect genes in their families did not take Fletcher's position sitting down.

Marjorie Guthrie, widow of folk singer Woodie Guthrie who died from a genetic disorder (Huntington's chorea), asserted that persons who carry genes for serious genetic diseases do have a right to reproduce and that the desire to procreate is deep-seated and precious to most humans. Arno G. Motulsky, professor of medical genetics at the University of Washington School of Medicine in Seattle, was among those who agreed with her.

The confrontation between Fletcher and Guthrie points out one of the many ethical-legal questions raised by the "new genetics": Should attempts be made to prevent genetic defects through family counseling and amniocentesis? Other questions relate to such techniques as artificial insemination and *in vitro* fertilization. Currently there are no firm replies to most of these questions, primarily because the U.S. legal system has barely begun to grapple with them.

Let's look, for example, at several questions surrounding genetic disease prevention through amniocentesis, the process by which fluid is withdrawn from the womb and used to diagnose a variety of fetal chromosomal and genetic defects. If such defects are detected, pregnant women can opt for a therapeutic abortion. When should an obstetrician alert a patient to the availability of amniocentesis? Certainly when a patient is known to carry genes for a serious disease, replies Aubrey Milunsky, a medical geneticist at Massachusetts General Hospital. And certainly when a patient is 35 years old or older, he says, because the risk of Down's syndrome (mongolism) and those of other fetal chromosomal abnormalities increase with maternal age. The reason that physicians

## Moral philosophers and an outdated legal system are faced with complex questions raised by advances in genetics and related fields

BY JOAN AREHART-TREICHEL

should make such recommendations, he explains, is that patients have a right to be informed of any increased risks. Cases have already arisen in which women who gave birth to genetically defective children brought suit against doctors who failed to inform the women, while pregnant, of the availability of amniocentesis.

As amniocentesis becomes available for diagnosing more and more of the 2,000 known genetic diseases, will more and more parents of genetically defective children collect damages from physicians for economic and emotional harm to themselves and their children resulting from a negligent failure to detect the defect and to offer to terminate the pregnancy? Yes, as soon as the courts free themselves from the confused notion that no one can sue for "wrongful life," predicts Alexander Morgan Capron, professor at the University of Pennsylvania Law School.

Will genetically defective children bring suits against their parents for "wrongful birth"? No, contends Margery W. Shaw of the University of Texas Health Science Center in Houston. Speaking as the only medical geneticist-lawyer in the United States, she points out that the courts have so far been slow to allow family members to sue each other, and no court has yet permitted a child to sue its parents for wrongful life. In other words, as a British lawyer attending the genetics and law symposium put it, "It would be mad for a child to sue his parents because his parents have to support him anyway. The only persons to benefit from such suits would be lawyers, and I speak as one."

Do prospective parents have a right to know the sex of their unborn fetus? Fetal sex is revealed by amniocentesis, but there is no legal precedent on this question, replies James R. Sorenson of Boston University School of Medicine. And amniocentesis centers differ in their policies regarding telling parents the sex of their fetuses for fear that the parents might use the information to abort fetuses not of the sex they desire. There are known instances of parents seeking amniocentesis ostensibly out of concern over the

possibility of having a genetically defective child, then using the information for sex selection.

Ethical-legal questions also surround reproduction by artificial insemination. Is there, for instance, a legal position stating which women can use artificial insemination to reproduce? No, replies George J. Annas, associate professor of law and medicine at Boston University School of Medicine. The selection of patients is up to the physicians who perform artificial insemination. So far physicians have used the technique mostly to help infertile women reproduce, but also to keep husbands from passing on genetic diseases and to help homosexual women who want to have children.

Can only certain kinds of sperm be used for artificial insemination? No, Annas continues. Physicians usually employ medical students as paid donors, but this is an arbitrary measure. Must sperm be genetically healthy before being used for artificial insemination? No, Annas says. Some physicians ask a few questions about common genetic diseases in the donors or close relatives, but rarely take a detailed pedigree or perform genetic lab tests.

Who is the legal father of a child born by artificial insemination? Some courts, Shaw says, have addressed that question, and many states have passed statutes that make the child the legitimate child of the husband of the mother if he has consented to the procedure. However, 70 percent of physicians who perform the technique do not keep records of sperm donors in order to safeguard donors from paternity suits, Annas points out, and about one-third of the physicians doing the technique mix sperm from several donors to further safeguard donors from paternity lawsuits.

Are these practices ethical? No, Annas contends. Children conceived by artificial insemination have a right to know their genetic heritage — whether they have a particular genetic disease or carry defective genes. "Concern for donors' self-protection," he argues, "should give way to concern for the child." Melvin L. Taymor, clinical professor of obstetrics and gynecology at Harvard Medical School, disagrees: "Many men would not donate sperm if they didn't have privacy. I would like to see more evidence that there is genetic or other harm to offspring before such secrecy is removed. I think that opening the records of sperm donors would cause tremendous harm."

Whether offspring conceived by artificial insemination should know their genetic backgrounds raises a related ques-

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tion: Should adopted children know their genetic heritage so they know whether they have, or carry, a specific genetic disease? John R. Ball, physician, lawyer and senior policy analyst for the Office of Science and Technology Policy in Washington, replies: Although state laws are moving toward statutes that would allow adoptees to obtain genetic information while respecting the privacy of the natural parents, few state laws require genetic parents to provide genetic information about their families at the time they give up their offspring for adoption. It would be beneficial to adoptees if they knew their genetic history, Ball holds, because many genetic diseases have available methods of treatment, and because many genetic diseases can be diagnosed in the womb.

An even more difficult question arises: When should genetically defective persons receive medical treatment that will prolong their lives? A landmark court case dealt with this question, reports Charles H. Baron, professor of law at Boston College Law School. The case was brought before the Massachusetts Supreme Court in 1977 to decide whether Joseph Saikewicz, a mentally retarded patient, should receive medical treatment for his leukemia — a treatment that would extend his life by only a few months. In other words, the question was whether a short extension of life would be a curse or a blessing for a retarded person. The court ruled that it was better to withhold than to give treatment.

This case, however, has left the medical community with confusing legal guidelines over what they should do in future cases of this nature. Should they try to arrive at such decisions through the courts? Baron thinks so. Arnold S. Relman, professor of medicine at Harvard Medical School and editor of the *NEW ENGLAND JOURNAL OF MEDICINE*, strongly disagrees: "I fail to see how a judge, a total stranger, getting information from lawyers who are trained to fight each other, can really know what the patient would like under these circumstances." Relman believes that physicians should decide.

Robert A. Burt, professor at Yale University Law School, takes a compromise stance. He contends that courts and legislatures can provide general guidelines for a physician's conduct in terminating medical treatment for a retarded (or comatose) patient, but that these guidelines should be applied by courts only in after-the-fact review. In any individual case, Burt says, the physician and family members should be forced to accept the responsibility for making and acting on the treatment decision with the clear knowledge that a court might later rule that they had acted wrongfully. Why this posture? "I think the Saikewicz case showed that neither the judge nor the physicians took true responsibility for terminating Saikewicz's treatment," Burt replies. "Each

pretended that the other was taking the basic responsibility for action, and in this mutual charade Saikewicz's individual circumstances were hopelessly obscured."

Still a fourth position on the question is held by Robert M. Veatch, senior associate with the Institute of Society, Ethics and Life Sciences in Hastings-on-Hudson, N.Y.: The patients' families should make these decisions.

But probably the toughest questions at this point surround reproduction by *in vitro* fertilization and embryo transfer — what is popularly known as test-tube reproduction. There are at least three potential uses for this technique, explains Barbara F. Katz, staff attorney with the Massachusetts Department of Public Health (SN: 6/2/79, p. 358). A woman with blocked Fallopian tubes could donate an egg to be fertilized in tissue culture by her husband's sperm, and then the fertilized egg would be transferred back into her womb for development. A woman with blocked Fallopian tubes could donate an egg to be fertilized by sperm from someone other than her husband, and the fertilized egg would be transferred back into her womb for development. Or a woman who had healthy Fallopian tubes, but who did not want to carry her own baby throughout pregnancy, could donate an egg to be fertilized by her husband's sperm in culture, and then the fertilized egg would be transferred into the womb of another woman (surrogate mother) to be carried to term. Each of these uses raises legal questions, says Katz, but especially the last.

Who would be the mother of the conceptus? The egg donor? The surrogate mother? If a surrogate mother were being paid for her services and a payment was missed, would the child she was carrying become hers? What if amniocentesis detected a defect in the fetus? Would the egg donor or the surrogate mother have the right to decide on an abortion? What if the egg donor died before birth of the fetus? Would the surrogate mother then become the legal mother?

Although legal requirements for government-funded *in vitro* fertilization and embryo transfer are starting to emerge, Katz reports, the legal aspects of human *in vitro* fertilization and embryo transfer conducted without government funds have yet to be tackled.

When will the above questions receive firmer ethical and legal responses? Not next year, or the next, and maybe not even for many years to come, says Elliot L. Sagall, president of the American Society of Law and Medicine. The U.S. legal system, he contends, is one generation behind medical science. Will the legal system catch up? Will the questions ever be satisfactorily answered? If there was one thing upon which participants at the law and genetics symposium did agree, it was that discussing such questions is a first step toward resolving them. □

### ... Jupiter

tude traversed by Io in a Jovian rotation, which would have produced a much thicker torus. Since they were indeed seen only in a thin, magnetic equatorial band, perhaps, Pilcher offers, they are created only at magnetic latitudes near 0°, when Io is actually in the equatorial plane. It is even possible that the narrow, magnetically confined ring existed on both nights, but was masked on the second night by the substantial amount of the lower temperature emission.

To make the picture still more complicated, it could be inferred from the images (though Pilcher is reluctant to commit himself) that changes take place in the torus on time scales considerably shorter than a day. One can get the impression that the 5.3-R<sub>J</sub> circle Pilcher matched to the April 9 photos, for example, does not fit with the same degree of precision in each case. The 5.3-R<sub>J</sub> size, in fact, as he acknowledges, was only an approximation, adopted to suit images that actually seem to range from about 5.0 to as much as 5.5 R<sub>J</sub>. A smaller range — about 5.7 to 5.9 R<sub>J</sub> — may be represented by the following night's views.

The mere presence of the veils, tori and other phenomena associated with Io is bizarre enough, and the possibility that those vast effects change rapidly on a scale large enough to see from earth is more striking still. But more work remains to be done — and nothing on Io is ordinary. □

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**ASBESTOS: Volume I, Properties, Applications, and Hazards** — L. Michaels and S. S. Chisick, Eds. — Wiley, 1979, 553 p., illus., \$62.50. An attempt to bring together the fundamental and essential information on asbestos. This volume, the first of two, covers the basic science of asbestos; its mineralogy, chemistry and physics; its effect on the health of people exposed to it; monitoring and identification of airborne asbestos; use in building; and alternatives.

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