

effort by the medical societies or the FDA. Findings of a study recently submitted for publication by a Johns Hopkins researcher, however, are not very encouraging. Neil Holtzman, an associate professor of pediatrics and a key researcher in alpha-fetoprotein testing, conducted an experiment in 1980 that evaluated obstetricians' knowledge about the test procedures after they were taught about the technique. Holtzman looked at three groups: one set of about 25 doctors were given oral and written instruction about the test and then used the test to screen patients with the help of a coordinator; other doctors were instructed about the test but did not do any screening; the control group comprised physicians who were not formally taught about the test.

Holtzman found that, even after instruction and practice in screening, physicians demonstrated no better knowledge of the test than the controls or the other group. He says that many physicians in the screening program "did not know when the tests should be administered and did not know how to follow up" when quizzed about the procedures. One surprising finding of the study is that no unnecessary abortions were performed among the 1500 participating women. Holtzman suggests that the physicians relied heavily on the coordinator to guide them through the process.

Supporters of federal restrictions emphasize the need to evaluate a laboratory's ability to analyze the serum samples, as highlighted by a 1982 study by the Centers for Disease Control (CDC). The agency sent various samples to 16 labs which were known for their dependability. Vincent Przybyszewski, one of the researchers, says that the labs showed wide variation in their results on the same samples. They achieved only 80 percent agreement on specimens that had either very high or very low levels of alpha-fetoprotein. No agreement was reached with samples that were borderline cases.

In the opinion of James Macri, director of the neural tube defect laboratory at the State University of New York at Stony Brook, the CDC results "were chaotic." Macri says that based on his experience, accumulated from the Stony Brook program which has screened some 60,000 women for fetuses with neural tube defects, a lab should do a minimum of 400 assays a week to ensure proficiency. The large sampling would also help the lab more accurately calculate normal values for alpha-fetoprotein levels, which vary from one community to another. Macri's recommendation is

Fetal Surgery for Neural Defects?

Pregnant women who learn that they are carrying a fetus with a neural tube defect are faced with a difficult choice. They can have an abortion or they can carry the fetus to term, realizing that the chances are high that the child will be handicapped. Although some children with neural tube defects have no or only minimal handicaps, most are paralyzed below the waist and have no bowel or bladder control. Most are also mentally retarded.

In the future, however, fetal surgery to correct neural tube defects may provide an option between abortion and a handicapped child. Gary Hodgen of the National Institute of Child Health and Human Development (NICHD) and Maria Michejda of Georgetown University School of Medicine are developing methods for treating fetuses with encephaloceles and spina bifida. So far, they have had some surprising results with monkey fetuses, but much more work is required before their technique could be applied to humans.

Techniques developed by Hodgen and his associates have already led to the use of fetal surgery to correct hydrocephaly. This condition—in which fluid builds up in the ventricles of the brain, causing such pressure that the brain may be irreversibly damaged—is the major cause of mental retardation in children with spina bifida. Most babies with hydrocephaly are treated after birth, but by then much of the damage is already done.

Several years ago, Hodgen and his associates at the NICHD developed a shunt to treat hydrocephalus in utero. They tested the shunt, which drains excess fluid from the brain, in monkey fetuses and found that the treated monkeys seemed to have normal brain functions. Untreated hydrocephalic monkeys had serious brain damage, often dying within a few days of birth because they could not nurse or suck from a bottle. The technique proved so successful in monkeys that some physicians recently decided to try treating unborn babies. So far, too few human fetuses have been treated to assess the results.

Now Hodgen and Michejda are developing a way to treat encephaloceles—a neural tube defect in which a portion of the brain protrudes through the skull—by fetal surgery. The standard treatment, after birth, is to surgically remove the protruding brain tissue and close the skull. Because the part of the brain pushed out includes the visual cortex, babies born with encephaloceles usually are blind and often are mentally retarded.

Hodgen and Michejda can produce encephaloceles in monkey fetuses by giving the mother a synthetic corticosteroid. During the second trimester they open the uterus, partially pull out the fetus, and cut off the protruding brain. They then seal the skull with bone paste—a mixture made of ground fetal bones and culture medium—and return the fetus to the womb, preventing spontaneous abortions by using drugs to relax the uterus. Surprisingly, the brains of the monkey fetuses regenerate in utero and the monkeys are born fully able to see.

"We have studies under way to correct spina bifida," says Hodgen, "and we are trying to develop an adequate model." It has proved difficult to produce spina bifida in monkeys by giving them teratogens, so Hodgen is producing the defect surgically. He cuts into the fetus' back, allowing the nerve bundle to hemorrhage. Then he uses bone paste to close the opening in the spine in order to allow the spinal nerves to regenerate.

Surgical treatment of neural tube defects in human fetuses is still a long way off, however, and use of the technique would raise difficult ethical problems. For example, it will be necessary to have sources of fetal bones. Hodgen believes that once the need is known, parents would donate the bones of spontaneously aborted fetuses, just as they now sometimes donate the organs of young children who are brain-dead.

Hodgen says that his goal in trying to correct neural tube defects is to give these babies a chance for a normal life if their disease is detected in utero by alpha-fetoprotein tests. "We have an obligation, given the value we put on the quality of human life, to try to offer women other alternatives," than abortion, he says.—GINA KOLATA