

tice suit if they don't offer it.

"We all feel public pressure to get on with it," says Nancy Lamontagne of the National Institute of Diabetes and Digestive and Kidney Diseases. And that is why she, along with Elke Jordan of the NIH genome center, and the American Society of Human Genetics are hastily putting together a February workshop to tackle the plethora of questions surrounding the new test.

One of the first questions is simply how sensitive the test must be for widespread screening. Most agree that 70% is not good enough, but is 90%? 95%? 99%? The same question came up with alpha-fetoprotein testing, which detects neural tube defects and other problems, says Neil Holtzman of the Johns Hopkins University School of Medicine. "The question then was how can you withhold tests and continue to see kids born with these defects?"

Even fundamental questions like who should be tested, and when, must be sorted

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out. Although cystic fibrosis is primarily a disease of Caucasians, the gene does occur, at about one-tenth the frequency, in American blacks as well. Should everyone be screened, as Kaback advocates, or should screening be limited to Caucasians, as the President's ethics commission concluded in 1983? And should they be tested as newborns, adolescents, or later in life?

The goal is to test people before they conceive, while they still have a number of options. But how do you reach them beforehand? It hasn't worked well in the past, concedes Beaudet. "If you look at what has happened with other diseases, most couples are tested when they are pregnant."

Where the test is offered will make a difference. The most efficient way to reach people of reproductive age is to offer the test as part of obstetrical care, says Holtzman, perhaps piggybacking it onto prenatal tests already offered. If a woman tests positive, then her partner would come in for testing.

But if the goal is to provide information to make informed reproductive decisions, then an obstetrician's office may not be the way to go, counters Kaback. If screening is offered through a doctor's office, he says, it will almost invariably be done when the woman is pregnant.

The alternative would be a community-based screening program, perhaps modeled on the Tay-Sachs program that Kaback

helped start in the early 1970s, which offered testing through synagogues, community centers, and the like (see box on p. 18). But for cystic fibrosis, the numbers are daunting. "There might be a way to figure out how to do it logistically," says Elena Nightingale of the Carnegie Corporation of New York, "but where do you find the workers when you are talking about screening that many people?"

And who is going to educate the public about the test and then counsel those who are positive? "Screening without education and counseling would be a catastrophe," asserts Kaback.

Collins agrees: "One in 25 Caucasians is a carrier. That means 8 million Americans. And every one of them deserves an explanation. The problem, says Jessica Davis, codirector of the Center of Human Genetics at Cornell University Medical College, is that "there simply aren't that many card-carrying clinical geneticists and counselors around."

All this assumes that everyone will want to be tested, which is not at all clear. Alpha-fetoprotein testing, for example, is now routinely offered to pregnant women in this country who receive prenatal care, but only about 40% elect to have it, says Lanciano of Integrated Genetics. He believes that, likewise, demand for the cystic fibrosis test may be much lower than many geneticists are now predicting. So does Holtzman, who points out that just one-fourth of young Jewish adults are screened for Tay-Sachs disease. And mass screening depends on a

reliable and cheap test, which so far does not exist. The test is now going for anywhere from \$125 to \$225 a pop; for mass screening, says Brown, the upper limit is about \$50.

Kaback is calling for pilot programs, similar to those he ran for Tay-Sachs, to evaluate, among other things, which educational approaches work best, how many people elect to be tested, just what the counseling needs are, and "how much fear we create." And even before those studies are done, he and others say, some type of centralized quality control must be set up to monitor the laboratories already offering the test. They'd better hurry, says Brown of Gene Screen. "To [expect us to] wait until we get 99% of the mutations and a national program is defined in 2½ years, that's kind of dreaming. The genetics community is thinking about how to make it happen ideally. Forget it, that game is already lost. The question is, how can the genetics community make it to happen better?"

It's just a matter of time, Brown says, before *Cosmo* or *Redbook* runs an article that will educate a lot of women about the test. "It will educate lawyers too. And the first lawsuit against someone who didn't offer the test will get a lot of attention." At some point, he says, one of the companies is going to decide that the test is good enough, that obstetricians are ready, and "go for it." Adds Brown: "And once one company starts offering it, it will be very difficult for others to hold back." ■ **LESLIE ROBERTS**

Article on Gallo Prompts Inquiry

A 50,000-word investigative opus in the 19 November 1989 issue of the *Chicago Tribune* has given new life to a protracted controversy over who should get the credit for nailing down the cause of AIDS and has prompted preliminary inquiries by Congress and the National Institutes of Health.

The article has caught the attention of Representative John D. Dingell, the Michigan Democrat who last year held a series of widely publicized hearings on scientific misconduct. In a 5 December letter to William Raub, acting director of NIH, Dingell said the article "raises disturbing new issues concerning Dr. [Robert C.] Gallo's role in the discovery of the HIV virus." Dingell asked Raub whether NIH has investigated any of the specific allegations contained in the article and, if it hasn't, when it plans to do so. The letter, a copy of which was obtained by *Science*, criticizes NIH for a history of "[turning] a blind eye to misconduct by senior scientists supported by federal funds.

We trust that this will not be the case in the present situation." News of the letter first appeared in *Science and Government Report*.

The *Tribune* article, written by investigative journalist John Crewdson, details the events that led to the discovery of the AIDS virus—now called HIV—and the subsequent dispute over the importance of the roles played by Gallo's lab at the National Cancer Institute in Bethesda and Luc Montagnier's lab at the Pasteur Institute in Paris. Crewdson implies that rather than developing his own strain of HIV, Gallo actually made extensive use of a viral isolate provided to him by Montagnier. Crewdson also raises questions about inaccuracies in laboratory records and discrepancies between notebooks and subsequent journal articles.

Despite Dingell's request for a response by 21 December 1989, as *Science* goes to press an NIH spokesman had no comment about what would be done to address the congressman's concerns. ■ **JOSEPH PALCA**