

In 1990 cardiologists began to suspect a linkage between heart disease and the condition of having two genes called apo E4. Tens of thousands of people now have been tested for this condition. Most, however, do not know their test results, because the tests were part of a battery, and doctors seldom report each test result to test subjects. In 1993 medical researchers determined that the same condition --having two apo E4 genes --predicts with a high probability (as high as 90%) the risk of developing Alzheimer's disease before the age of eighty. Unlike heart disease, Alzheimer's disease has no known treatment. Medical researchers now want to study the people who had apo E4 tests done on them in connection with heart disease to assess their mental abilities as they age. The researchers are deeply troubled, however, about approaching these individuals, most of whom, as just noted, have no knowledge of their high risk condition.

Should these individuals be notified? If so, why, If not, why not?

MODERATOR'S ANSWER: In this case the individuals tested in 1990 for apo E4 should not be notified that they are significantly at risk of developing Alzheimer's disease before the age of eighty, given that this information will not enable them to take any steps toward reducing the risk. The assessment of changes in mental ability with age could play a role in developing a treatment for Alzheimer's disease. At this time, however, one cannot describe such a study as the search for a missing piece in a puzzle where researchers have already found most of the other pieces. This case thus seems to involve choosing between a near certainty of causing significant harm and a possibility of preventing such harm. It would seem the choice should be to avoid causing the harm.

Case from the February 24, 1996 Intercollegiate Ethics Bowl. Copyright Robert Ladenson, Center for the Study of Ethics at the Illinois Institute of Technology, 1996.