The recent identification of the gene associated with cystic fibrosis (CF) offers great hope for new treatments for this common disease. Even more immediately, it is now possible to identify healthy individuals who carry the CF trait. However, the current test detects only 70% of carriers, and there is little experience in the delivery of such complex information to large populations. Accordingly, there are serious reservations, and there is no consensus among geneticists regarding widespread screening for CF carriers at this time.

However, there is consensus on a number of issues. First, carrier testing should be offered to couples in which either partner has a close relative affected with CF. Second, one or a few federal, foundation, or privately supported pilot programs should be conducted as soon as possible in order to gather more data regarding laboratory, educational, and counseling aspects of screening. Third, there is an immediate need for centralized quality control of laboratories conducting these tests. Fourth, it will be appropriate to begin large-scale population screening in the foreseeable future, once the test detects a larger proportion of CF carriers and more information is available regarding the issues surrounding the screening process. Until that time, it is considered premature to undertake population screening.

Finally, while it is recognized that testing of highly motivated individuals in the general population may occur, it is the position of The American Society of Human Genetics that routine CF carrier testing of pregnant women and other individuals is NOT yet the standard of care in medical practice.

A working group of The American Society of Human Genetics is being formed to further explore the issues raised by this exciting new technology.