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THE CODE SAYS
AMA *Code of Medical Ethics*' Opinions on Genetic Testing

Opinion 2.131 - Disclosure of Familial Risk in Genetic Testing
(1) Physicians have a professional duty to protect the confidentiality of their patients' information, including genetic information.

(2) Pre- and post-test counseling must include implications of genetic information for patients' biological relatives. At the time patients are considering undergoing genetic testing, physicians should discuss with them whether to invite family members to participate in the testing process. Physicians also should identify circumstances under which they would expect patients to notify biological relatives of the availability of information related to risk of disease. In this regard, physicians should make themselves available to assist patients in communicating with relatives to discuss opportunities for counseling and testing, as appropriate.

(3) Physicians who order genetic tests should have adequate knowledge to interpret information for patients. In the absence of adequate expertise in pre-test and post-test counseling, a physician should refer the patient to an appropriate specialist.

(4) Physicians should encourage genetic education throughout a medical career. Based on the report "Disclosure of Familial Risk in Genetic Testing," adopted June 2003.

Opinion 2.137 - Ethical Issues in Carrier Screening of Genetic Disorders
All carrier testing must be voluntary, and informed consent from screened individuals is required. Confidentiality of results is to be maintained. Results of testing should not be disclosed to third parties without the explicit informed consent of the screened individual. Patients should be informed as to potential uses for the genetic information by third parties, and whether other ways of obtaining the information are available when appropriate.

Carrier testing should be available uniformly among the at-risk population being screened. One legitimate exception to this principle is the limitation of carrier testing to individuals of childbearing age. In pursuit of uniform access, physicians should not limit testing only to patients specifically requesting testing. If testing is offered to some patients, it should be offered to all patients within the same risk category. The direction of future genetic screening tests should be determined by well-thought-out and well-coordinated social policy. Third parties, including insurance companies or employers, should not be permitted to discriminate against carriers of genetic

disorders through policies which have the ultimate effect of influencing decisions about testing and reproduction.
Based on the report "Ethical Issues in Carrier Screening for Cystic Fibrosis and Other Genetic Disorders," adopted June 1991.

Opinion 2.138 - Genetic Testing of Children
Genetic testing of children implicates important concerns about individual autonomy and the interest of the patients. Before testing of children can be performed, there must be some potential benefit from the testing that can reasonably be viewed as outweighing the disadvantages of testing, particularly the harm from abrogating the children's future choice in knowing their genetic status. When there is such a potential benefit, parents should decide whether their children will undergo testing. If parents unreasonably request or refuse testing of their child, the physician should take steps to change or, if necessary, use legal means to override the parents' choice. Applying these principles to specific circumstances yields the following conclusions:

(1) When a child is at risk for a genetic condition for which preventive or other therapeutic measures are available, genetic testing should be offered or, in some cases, required.

(2) When a child is at risk for a genetic condition with pediatric onset for which preventive or other therapeutic measures are not available, parents generally should have discretion to decide about genetic testing.

(3) When a child is at risk for a genetic condition with adult onset for which preventive or other therapeutic measures are not available, genetic testing of children generally should not be undertaken. Families should still be informed of the existence of tests and given the opportunity to discuss the reasons why the tests are generally not offered for children.

(4) Genetic testing for carrier status should be deferred until either the child reaches maturity, the child needs to make reproductive decisions, or, in the case of children too immature to make their own reproductive decisions, reproductive decisions need to be made for the child.

(5) Genetic testing of children for the benefit of a family member should not be performed unless the testing is necessary to prevent substantial harm to the family member.

When a child's genetic status is determined incidentally, the information should be retained by the physician and entered into the patient record. Discussion of the existence of this finding should then be taken up when the child reaches maturity or needs to make reproductive decisions, so that the individual can decide whether to request disclosure of the information. It is important that physicians be consistent in disclosing both positive and negative results in the same way since if physicians raise the existence of the testing results only when the results are positive, individuals will

know what the results must be. This information should not be disclosed to third parties. Genetic information should be maintained in a separate portion of the medical record to prevent mistaken disclosure.

When a child is being considered for adoption, the guidelines for genetic testing should be the same as for other children.
Based on the report "Testing Children for Genetic Status," adopted June 1995.