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American Medical Association Adopts New Direct-To-Consumer Genetic Testing Policy Recommendations

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At its June 17 annual meeting, the American Medical Association (AMA), the largest physician group in the United States, adopted policy recommendations opposing direct-to-consumer (DTC) genetic testing. The recommendations state that a health care professional should be involved in the genetic-testing process, and encourages individuals interested in obtaining genetic testing to contact a health care professional.

Prior to these recommendations, the AMA had more general policies discouraging DTC genetic testing. At its 2007 annual meeting, the American College of Obstetricians and Gynecologists' Massachusetts Delegation introduced a resolution asking the AMA to study the issue. AMA members voted to adopt the resolution. Subsequently, AMA staff reviewed the state of DTC testing, and presented a report with recommendations at the AMA annual meeting. The new recommendations note that DTC genetic testing is available, and make it clear that the AMA believes that it is necessary for genetic tests to be carried out under the supervision of a health care professional. "Encouraging all genetic testing to require supervision by a qualified health care professional, ensures they are being properly used and the results are being accurately interpreted and understood by patients," said AMA board member William Hazel.

The recommendations include three directives for the AMA: to work with other organizations to develop criteria for advertising DTC genetic testing, to encourage the U.S. Federal Trade Commission to vet the accuracy of DTC advertisements, and to educate physicians on what genetic tests are available so that they can counsel their patients on the limitations of the tests.

The AMA's recommendations follow the American College of Medical Genetics' (ACMG) and the American Society for Human Genetics' (ASHG) statements on DTC genetic testing. ACMG recommended that a genetics expert be involved in ordering and interpreting genetic tests, consumers be made fully aware of the capabilities of genetic tests, the scientific evidence on which tests are based be available and stated so that the consumer can understand it, the laboratories conducting the tests be accredited, and consumers be made aware of privacy issues associated with DTC genetic testing.

ASHG's January 2007 recommendations , co-authored by GPPC's Kathy Hudson and Gail Javitt, recognize that some tests can be appropriately offered directly to consumers, provided that specific safeguards are in place to ensure test quality and adequate information disclosure. For example, ASHG states that companies offering DTC genetic testing should inform consumers of the benefits and limitations of the tests, the scientific evidence supporting the claims being made about the test, any risks to the consumer, and the company's certification status and privacy policies. ASHG further recommends that professional organizations educate their members so that they can counsel patients about the benefits and limitations of DTC testing. Finally, ASHG recommends that government agencies take specific actions to ensure the analytic and clinical validity of genetic tests offered DTC, and the truthfulness of claims made about the tests. - *Katherine Groff*

Issue brief - Direct-to-consumer genetic testing: empowering or endangering the public?

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