

American Medical Women's Association
Position Paper on Genetic Testing for Breast and Ovarian Cancer Susceptibility

Scientific advances have made it possible to identify a growing number of genetic alterations predisposing a woman to breast and/or ovarian cancer. Genetic testing to detect cancer risk in asymptomatic individuals is likely to become available on a widespread basis to the general public in the near future. To ensure the responsible, ethical, and legal use of this information, the following recommendations are made:

1. Legislation to protect the individual should be enacted at the state and federal levels as soon as possible to address the multiplicity of issues that will emerge as a result of genetic testing.
 - a. Required counseling for patients submitting to genetic testing both before and after testing
 - b. Required mechanisms of confidentiality for those individuals or organizations holding genetic information, so that it cannot be released without the expressed written consent of the individual to whom the results belong
 - c. Required provision of health and life insurance coverage for those individuals who consent to genetic testing under research protocol conditions
 - d. Prohibition of both health and life insurers to deny, limit, or otherwise control the coverage, eligibility, continuation, enrollment, or contribution requirements of individuals based on genetic testing information, or requests for genetic services
 - e. Prohibition of both health and life insurers to establish differential rates or premium payments based on genetic information or an individual's request for genetic services
 - f. Prohibition of employers or employment agencies from discriminating against an individual because of genetic testing results
 - g. Prohibition of any agencies, organizations, or individuals from requiring an individual to submit to genetic testing or to disclose or collect results of testing
 - h. Prohibition of minors or individuals deemed incompetent for submission to genetic testing for breast and/or ovarian cancer susceptibility
2. Until legislation is enacted to protect the individual's rights as outlined above, the following principles should be used to guide decisions about genetic testing:
 - a. Prior to the testing of any individual for a genetic predisposition to breast and/or ovarian cancer, one or more pretest counseling session(s) should be conducted. Topics should include:
3. Education about breast and ovarian cancer risk and genetic inheritance, including risks of contracting either disease by a given age depending on whether the genetic mutation has been inherited or not

4. Accuracy of test results, including false positives and negatives
5. Limitations regarding confidentiality of results
6. Potential medical interventions that may be pursued if a woman is shown to have inherited a gene mutation, and the potential efficacy of these interventions, including a complete disclosure of the known risks and benefits of any surgical interventions
7. Potential psychological consequences of receiving test results, including its impact on the individual and the family unit, including biological offspring, if results are disclosed
8. Potential discrimination that may result if an individual tests positively for disease susceptibility, including but not limited to discrimination in employment and health and/or life insurability
 - a. Following consent for genetic testing, the individual should be given the option of deciding not to learn the results of the test.
 - b. If an individual decides to learn the test results, post-test result counseling should be done to reinforce the issues outlined above and to assist the individual in full comprehension of the implication of the test results
9. Because the field of genetic testing for susceptibility to breast and/or ovarian cancer is in its infancy, all testing is strongly encouraged to be done in the research setting, including research into the chosen interventions pursued by individuals who test positively for the genetic mutation(s) and the outcomes of those interventions.

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