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SENATE JOINT RESOLUTION NO. 372
AMENDMENT IN THE NATURE OF A SUBSTITUTE

(Proposed by the House Committee on Rules
on February 16, 1995)

(Patron Prior to Substitute—Senator Howell)

Establishing a joint subcommittee to study the legal and policy ramifications of breast cancer susceptibility gene research.

WHEREAS, breast cancer is the most common cause of death among women 30 to 54 years of age; and

WHEREAS, in the opinion of some experts, the incidence of breast cancer has reached epidemic level, with one out of every eight women living in the Commonwealth predicted to be affected; and

WHEREAS, although early detection is important in effective treatment, there is currently no medically effective, cost-effective, or safe method to screen for breast cancer in women under the age of 50; and

WHEREAS, it is estimated that as many as 45 percent of those women diagnosed with breast cancer before the age of 40 carry a breast cancer susceptibility gene; and

WHEREAS, the National Plan on Breast Cancer has adopted as one of its six priorities the implementation of "a comprehensive plan to address the needs of individuals carrying breast cancer susceptibility genes"; and

WHEREAS, the National Institute of Health and the Department of Defense are increasing research funding of hereditary breast cancer studies, funding for which Virginia researchers will be competing; and

WHEREAS, all genetic research raises ethical and legal issues related to societal perceptions, public and private third-party-payer systems, privacy, confidentiality, counseling, treatment, and discrimination; and

WHEREAS, because breast cancer is a complex disease with multiple causes, the likelihood of all individuals identified as carrying a susceptibility gene actually developing the disease is remote; and

WHEREAS, future research into breast cancer will be greatly hindered if genetic information gathered for medical research or medical intervention is allowed to be the basis of discriminatory actions, thereby having a chilling effect on study participation; and

WHEREAS, if individuals who could benefit from the development of medical interventions emerging from breast cancer susceptibility gene research are reluctant to participate in the susceptibility gene research, the progress in defeating this disease could be slowed, thereby affecting the health of all Virginia's women and increasing the human and monetary costs of breast cancer; now, therefore, be it

RESOLVED by the Senate, the House of Delegates concurring, That a joint subcommittee be established to study the legal and policy ramifications of breast cancer susceptibility gene research. The joint subcommittee shall consist of nine members to be appointed as follows: four members of the Senate to be appointed by the Senate Committee on Privileges and Elections and five members of the House of Delegates to be appointed by the Speaker of the House. In its deliberations, the joint subcommittee shall examine ethical and legal issues, with the exception of matters pertaining to informed consent, which are related to the protection of individuals volunteering to participate in genetic research or who seek medical care involving genetic testing, including confidentiality and privacy concerns, life and health insurance coverage and reimbursement, employment discrimination, and other societal implications, such as the ability to obtain housing and credit.

During the course of its study, the joint subcommittee may also collaborate with the joint subcommittee established to study informed consent for medical procedures and treatment, pursuant to Senate Joint Resolution No. 313 (1995), to be apprised of the issues associated with informed consent for medical procedures and treatment and of the nexus between the issues to be examined, and to avoid duplicative efforts. In addition, the joint subcommittee shall seek the perspectives and expertise of individuals who have experienced breast cancer, medical ethicists, medical researchers, physicians, nurses, counselors, other health care practitioners, and other interested parties.

The direct costs of this study shall not exceed \$5,400.

The Division of Legislative Services shall provide staff support for the joint subcommittee. All agencies of the Commonwealth shall provide assistance to the joint subcommittee, upon request.

The joint subcommittee shall complete its work in time to submit its findings and recommendations to the Governor and the 1996 Session of the General Assembly as provided in the procedures of the Division of Legislative Automated Systems for the processing of legislative documents.

Implementation of this resolution is subject to subsequent approval and certification by the Joint Rules Committee. The Committee may withhold expenditures or delay the period for the conduct of the

60 study.