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Symposium: Workshop on Inherited Breast Cancer in Jewish Women: Ethical, Legal, and Social Implications

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SYMPOSIUM: WORKSHOP ON INHERITED BREAST CANCER IN JEWISH WOMEN: ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS

INTRODUCTION

ON APRIL 26, 1996, the Law-Medicine Center and the Center for Biomedical Ethics at Case Western Reserve University held the first national workshop on the ethical, legal, and social implications associated with recent discoveries linking the BRCA1 breast cancer gene to a specific population, that of Ashkenazic Jewish women. The idea for this workshop originated with Tom Murray, Director of the Center for Biomedical Ethics at the School of Medicine; Eric Juengst, the first director of the ELSI program at NIH and now a professor at the School of Medicine, and myself. The three of us also served as moderators during the workshop. We wish to thank the Leonard and Harvey Krieger President's Endowment Fund for its generous support, without which this program would not have been possible.

In 1995, researchers identified a gene — BRCA1 — which appears to be associated with an elevated risk of breast cancer in some women. Initially, there was little interest in screening women for the BRCA1 gene because it had many mutations, each one of which would have to be tested for individually, but no single one of which was prevalent in a significant number of breast cancer patients. Later, researchers announced that one BRCA1 mutation is associated with breast cancer that affects one percent of all Ashkenazic Jewish women, and accounts for almost forty percent of the breast cancer cases in this population.

The possibility of population-based genetic screening for this mutation raises a number of ethical, legal, and social issues. In-depth discussion of these issues at the CWRU workshop provided significant insights for religious and community leaders, public health officials, clinicians and genetic counselors, and public policy analysts. The results of the workshop will be of further significance for ethnically based genetic screening programs in general, since it is expected that, in the future, researchers will discover many additional genetic mutations associated with disorders within specific ethnic groups.

The workshop was an informal exchange among invited experts in a variety of disciplines in a rapidly developing area. The discussion focused on seven papers that are being published in this symposium volume. An account of the workshop, prepared by Pulitzer Prize winning journalist B.D. Colen, has appeared in the newsletters of the Center for Biomedical Ethics and the Law-Medicine Center.

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