Background for H.R. BRCA Human Education and Awareness Requires Testing Act of 2020 (H.E.A.R.T.)

Everyone has BRCA1 and BRCA 2 genes. Some people have changes, called mutations, in these genes. One in 40 Ashkenazi Jewish women has a BRCA gene mutation.

Mutations in BRCA genes raise a person's risk for getting breast cancer at a young age, and for getting ovarian and other cancers. That is why Ashkenazi Jewish women are at higher risk for breast cancer at a young age.

On October 18, 2018, the Jewish Theological Seminary hosted a program on genetic cancer mutations in Ashkenazi Jews. At the start of the program, it was noted that those of Jewish ancestry have a 10 times greater risk of inheriting the BRCA gene mutations; 1 out of 40 carries the mutation, thereby increasing her/his risk for breast, prostate and ovarian cancers. Reference was made to the BRCA Founder Outreach Study. Its purpose is to expand knowledge of the BRCA mutations, motivate people, and give access to testing in the Ashkenazi community. The program was introduced by a rabbi who was a breast cancer survivor, who learned she had breast cancer while preparing for a prophylactic mastectomy, though she had completed a mammogram two months earlier.

Even though Ashkenazi Jewish women have a higher risk of breast cancer, genetic testing to screen for mutations linked to breast cancer in all Ashkenazi Jewish women is not the current standard of care.

Studies, however, have shown that Ashkenazi Jewish women who knew they were BRCA positive and chose to keep their breasts were much more likely to be diagnosed with noninvasive breast cancer, earlier stage invasive breast cancer, and needed less morbid cancer therapy; most importantly their survival was better.²

Initially, using these results, among other means, a large association of Ashkenazi Jewish women began lobbying³ Congress to argue for routine and covered BRCA screening in women of Ashkenazi Jewish descent. As the lobby gained traction and support across various constituencies, a bill finally reached the floor calling for genetic testing for the BRCA1, BRCA2, and other inherited gene mutations linked to breast cancer as part of annual checkups/physicals of all young women regardless of nationality or descent, offering patients the option to opt out.

¹ See https://www.bforstudy.com/, last visited February 28, 2020.

² https://www.breastcancer.org/research-news/ashkenazi-brca-status-and-bc-outcomes, last visited January 27, 2020

³ Information about the Ashkenazi Jewish women lobby and resulting Congressional Bill is fictional for the purposes of this Symposium.