

Good afternoon. Thank you for the opportunity to be here. My name is Ellen Engle. I am a resident of Montgomery County and a life-long Maryland resident. I am also an ovarian cancer patient/survivor and a volunteer Advocate Leader with the Ovarian Cancer Research Alliance. I am here today to urge you to pass the Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024) (SB0142).

For those who may not be familiar with ovarian cancer, it is the deadliest of the gynecologic cancers, and one of the deadliest overall. There is no screening mechanism for ovarian cancer. As a result, 85% of cases are diagnosed at late stages. The available treatments have a low success rate, leading to an overall 5-year survival rate of only 42%.

With no way to effectively screen for ovarian cancer, the latest recommendations are to try to prevent it, if possible. However, what steps a woman should take to do so is dependent on knowing one's genetic risk. A woman who has a BRCA mutation is encouraged to complete child-bearing by the age of 30, and to then have a preventive double mastectomy, complete hysterectomy, and salpingo-oophorectomy (removal of ovaries and fallopian tubes). A woman who does not have a BRCA mutation is encouraged to have her fallopian tubes removed if she is done with child-bearing and is having any other pelvic surgery. The only way to know into which category you personally fall (and therefore what actions to take) is to be tested. Knowledge is power, and gaining that knowledge is the only way for women to be empowered to take the appropriate recommended action.

However, many women are currently hesitant to get tested for fear that they will be discriminated against. They worry that insurance companies will deny them a policy, drop them from a current policy, or raise their rates so high that they will no longer be able to afford it. Even worse, they worry that their employer will find a way to fire them to avoid having to pay excessive rates if the insurance company finds out they have an employee with a known genetic risk. As long as these can and do happen, women will continue to eschew testing in order to keep their insurance, their jobs, and their incomes safe, but at the cost of not being able to take the necessary steps to protect their health, and potentially the health of their daughters, granddaughters, and future generations.

I strongly urge you to pass SB0142 and empower the women of Maryland to take the necessary steps to protect their health without jeopardizing their livelihoods or financial security. Thank you.