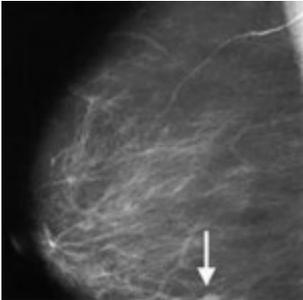


# A Call for More Expansive Breast Cancer Testing

By Gil Ross — September 28, 2015



[1] Credit:

[askanmd.blogspot.com](http://askanmd.blogspot.com)

Elizabeth Wurtzel, author of "Prozac Nation: Young and Depressed in America," among other works, recently wrote a *New York Times* [op-ed entitled](#) [2] "The Breast Cancer Gene and Me." Her piece, surrounded by heart-wrenching personal facts about her own situation, stresses that *all* women of the Ashkenazi branch of Jewish descent most Jews in America at least are of that eastern European heritage should get themselves tested for the BRCA genetic mutation. (In fact, there are two related mutations, BRCA-1 and -2, but for the purposes of her thesis and this discussion, we'll refer to them both as BRCA.)

Her poignant, fact-filled essay provides strong support for her alarm: that lineage has a 1-in-40 rate (2.5%) of BRCA positivity, as compared to a rate 1-in-400 (0.25%) rate among non-Ashkenazi women. The presence of the gene is associated with a frighteningly high risk of developing invasive breast cancer, and at a much younger age than is typical for non-carriers. The author cites an article from the [Journal of Clinical Oncology](#) [3] which gives a rate of between 56% and 84% for such carriers to eventually develop breast cancer.

"I did not know I have the BRCA mutation. I did not know I would likely get breast cancer when I was still young, when the disease is a wild animal," Wurtzel wrote. "I did not know I was a carrier because I do not fall within testing parameters. Most insurance companies cover testing specifically for Ashkenazi Jewish women only once we present with breast cancer. Before that doomed moment, testing is only for women who have a family history of BRCA or who have had breast cancer at a young age, or who have close relatives with the disease. But that is not how mutations operate. They are sneaky. I could not have guessed I am BRCA-positive."

Wurtzel lends further credence to her call for universal BRCA testing for Ashkenazis by pointing out the evidence that only one in 10 carriers are aware of their status, and that among carriers, only one half had any strong family history of breast cancer. As she puts it, "after a couple of generations of silence, it expressed itself through me. This happens frequently. Which is why insurers should cover BRCA testing for all Ashkenazi Jewish women."

This position is backed up by Dr. Elisa Port, chief of breast surgery at Mt. Sinai Medical Center,

who said "[a] large percentage of women who have the gene would not have been eligible to be tested." Meaning, that they would have to pay out-of-pocket for the test, given the current coverage rules which is what Wurzel's op-ed calls for changing.

Marcie Natan, president of the Jewish Women's Organization, Hadassah, was somewhat more circumspect about Ms. Wurtzel's demand. "The test sounds simple enough, Ms. Natan said, but understanding what to do with the results can be a complicated, gut-wrenching journey.

To which Wurzel responds, "Yes, it can. But not nearly so much as cancer."

The decision referred to, of course, is what to do if the test comes back positive. The answer for Ms. Wurtzel was easy: she already had cancer, so bilateral mastectomies was her decision.

For those apparently cancer-free when tested, the choices are: (1) do nothing, which raises the question of being tested in the first place; (2) frequent exams, including mammography with rapid surgery for any abnormality detected; or (3) bilateral mastectomies with reconstructive surgery upon being alerted to the result.

Some candidate women, for whom the prospect of having to make such a decision seems to heavy to bear, may opt to pass on getting tested. Another factor the issue involving insurance coverage is cost. Until 2013, the only testing lab was Myriad Genetics, and the BRCA test came to about \$3,000, not an inconsequential amount for many.

When the Supreme Court ruled that genes could no longer be patented, other companies sought to get in on the market; these late-comers charge quite a bit less, but their minimal track record on reliable testing makes some of them suspect.

To us, the obvious "answer" is to discuss the options and ramifications with your loved ones, and then with your doctor, before making any irrevocable decisions.

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[1] <http://acsh.org/wp-content/uploads/2015/09/Mammogram.jpg>

[2] [http://www.nytimes.com/2015/09/27/opinion/sunday/elizabeth-wurtzel-the-breast-cancer-gene-and-me.html?\\_r=0](http://www.nytimes.com/2015/09/27/opinion/sunday/elizabeth-wurtzel-the-breast-cancer-gene-and-me.html?_r=0)

[3] <http://jco.ascopubs.org/content/30/12/1321.full>