What can you really learn from undergoing multigene testing?

By ACSH Staff — September 23, 2014

It may seem like the idea that the more information, the better is true in the medical field. Yet, that’s not always the case. We see instances of overdiagnosis and overtreatment as a result of excess, unnecessary cancer screening tests. And now that a Supreme Court decision has resulted in the development of the field of multigene testing, we may begin to see how the above phrase applies in this area as well.

Currently, a host of companies are competing to expand the gene tests they offer as a result of new technology. And thousands of people are expected to take advantage of these new offerings, which go beyond the tests for the BRCA mutations associated with an increased risk of developing breast or ovarian cancer. However, in those cases, action can be taken such as having patients undergo screening more often or having the breasts or ovaries removed. In the case of the mutations that some of the newer tests may find, there may be no definitive action to be taken.

According to Dr. Kenneth Offit, chief of clinical genetics at Memorial Sloan Kettering Cancer Center in New York, Some genes were included because they could be tested, not necessarily because they should be. Testing companies are rushing headlong into this era, and individuals are getting results we’re not fully educated to counsel them on.

Some patients will be told that they have mutations called variants of unknown significance. Dr. Offit goes on, Patients are not getting closure. They’re walking out not knowing what to make of it. The only thing a doctor can tell a patient in this case is that they will have to wait until more is known about that specific mutation to take any action. Currently, an online registry created by Memorial Sloan Kettering and other institutions is in the works, in an effort to understand the link between certain mutations and cancer risk, but in the meantime patients are left to play the waiting game.

One woman whose results detected variants of unknown significance says, It’s better to be informed. But the New York Times article in which she was quoted asks, What has she been informed of?

ACSH’s Ariel Savransky had this to say. That’s a question that should be asked prior to
undergoing these genetic tests by both patients and their doctors. Patients should be counseled on just what the results of these tests may mean and be prepared to either be left with indefinite answers or be prepared to take action in the case of a result such as the presence of a BRCA mutation. Ultimately, just because we have the technology to do something does not mean that we should be using it, and until more is known about the mutations that are being tested for, the unnecessary stress that will result from a detection of a variant of unknown significance, is just that: unnecessary.

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