

genetest

From: Pamela Scudder <pscudder@windstream.net>
Sent: Saturday, February 18, 2012 6:32 PM
To: genetest
Subject: gene patenting

I understand that you are requesting public comments regarding the decision to issue patents to companies using human genes.

I very strongly discourage the further issuance of patents to any company for human genes. I have the BRCA 1 gene. Many, many members of my family also carry this genetic mutation. As a result of the patent currently held by Myriad Genetic testing labs many members of my family have been denied testing due to the cost. My daughter died of ovarian cancer. My other daughter and many other family members now have tested positive. Some were able to get 'grants' to assist with the costs, some had to pay out of pocket, and some were unable to have the test done. I was unable to get the test done when I first requested it because of the cost. There is no recourse, no second opinion, just Myriad deciding who virtually lives or dies at their whim, it seems like extortion. As a result, I had to wait until I was diagnosed with both ovarian and breast cancer. Even then, they didn't want to test. It was only after I prepared an extensive family medical history, that I was able to justify the need for testing. They will not share information they have about specific mutations. If one (mutation) is known to cause a higher incidence of pancreatic (for instance) cancer they won't tell anyone because it is 'proprietary information'. I don't care about their bottom line, I care about the lives of my family members and all others that carry these genetic mutations. Think about it, you too just may be affected by this or other genetic mutations. They, Myriad, recently identified another mutation, RAD51C. Now they charge an additional large amount to test for this in addition to the apx. \$3500 for regular testing. As more and more mutations are discovered, more and more families will continue to be denied the medical care they need by greedy companies just looking for a bigger bottom line.

I am grateful to be alive, but the current statistics for ovarian cancer are gloomy at best. I want to use every moment of my life to make people aware of the need for testing and the current system that allows corporations to own peoples genetic material. It is not right. Feel free to contact me for additional information.

Sincerely,
Pamela Scudder
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