

Not many people who have cancer, their cancer could have been prevented. I have advanced stage ovarian cancer that could have been prevented.

THE FIGHT TO TAKE BACK OUR GENES

My name is **Kathleen** _____. My prognosis is that I have a twenty percent chance of living for 5 years.

CHALLENGING PATENTS ON CANCER GENES

I remember the day that I got the call from my gynecologist. He said to me, “Oh honey you have ovarian cancer.”

THE U.S. SUPREME COURT IS ABOUT TO DECIDE WHETHER A PRIVATE COMPANT CAN OWN A PIECE OF YOU

After my surgery **Dr. DuPont** says to me, “Kathleen, after your surgery, your mother mentioned that your sister had breast cancer.” And I said, “Oh yes but our cancer isn’t genetic because she had the test and the testing was negative. “ And I will never forget that she put her head down and she looked back up at me and she said, “We’d like to see a copy of the tests.”

This is about WOMEN’s HEALTH.

Ellen Matloff: BRCA 1 and BRCA 2 are two genes that when mutated or changed increase the likelihood that woman will develop breast and ovarian cancer. The genes were found using many different researchers but they were patented by Myriad Genetics in the mid 1990’s. Many laboratories in the United States were offering BRCA 1 and 2 for testing. When MG began cracking down and closing labs, no one else could offer the test.

This is about ADVANCING SCIENCE.

When a patent comes to mind you think of a new invention. There was nothing new about what they were doing. But the comprehensive testing that they have developed looks for mutations within BRCA 1 and 2.

Kathleen: I believed that the test that my sister got was a comprehensive test. This is the gold standard of genetic testing that’s only done at this one lab and it comes back and it’s negative. And everybody in our family kinda goes, “Phew.”

This is about THE FIGHT AGAINST CANCER.

Ellen: But what we learned in the late 1990’s, early 2000’s is that “comprehensive BRCA analysis” was missing mutations in some families. I contacted Myriad genetics if we could offer a test for our patiesnt s who tested negative but in whom we really suspected we were missing something and we were told, “Absolutely not it’s a patent violation.” And so Myriad after many years developed **BART** testing to hopefully pick up those patients. Kathleen’s sister didn’t meet the high risk criteria to be included in Myriads **BART** analysis for free.

Kathleen: And her genetic counselor said, “Ok, because your sister has ovarian cancer now you meet the criteria.” Her genetic counselor tested her and the result was positive.

Ellen: Unfortunately, in that family, the mutation fell in the **Bart** region.

Kathleen: I’m like “what, what is going on, what do you mean it’s positive”. If she had had that two years ago it would have been a no-brainer for me to have a hysterectomy.

This is about THE RIGHT TO MAKE INFORMED DECISIONS.

Ellen: I think that this patent which has jacked up the prices and made testing more difficult in many circumstances may be preventing 100’s or maybe 1000’s and 1000’s of people from learning that they are at high risk for these horrible diseases.

This is about MORE THAN A COURT CASE.

Kathleen: I feel like this cancer has taken over my life and I live in fear every single day. I would love for them to say, this is bigger than us. Get rid of the patent. Let’s let other people get involved in this.

This is about TAKING A STAND.