

February 13, 2007

OP-ED CONTRIBUTOR

Patenting Life

By MICHAEL CRICHTON

YOU, or someone you love, may die because of a gene patent that should never have been granted in the first place. Sound far-fetched? Unfortunately, it's only too real.

Gene patents are now used to halt research, prevent medical testing and keep vital information from you and your doctor. Gene patents slow the pace of medical advance on deadly diseases. And they raise costs exorbitantly: a test for breast cancer that could be done for \$1,000 now costs \$3,000.

Why? Because the holder of the gene patent can charge whatever he wants, and does. Couldn't somebody make a cheaper test? Sure, but the patent holder blocks any competitor's test. He owns the gene. Nobody else can test for it. In fact, you can't even donate your own breast cancer gene to another scientist without permission. The gene may exist in your body, but it's now private property.

This bizarre situation has come to pass because of a mistake by an underfinanced and understaffed government agency. The United States Patent Office misinterpreted previous Supreme Court rulings and some years ago began — to the surprise of everyone, including scientists decoding the genome — to issue patents on genes.

Humans share mostly the same genes. The same genes are found in other animals as well. Our genetic makeup represents the common heritage of all life on earth. You can't patent snow, eagles or gravity, and you shouldn't be able to patent genes, either. Yet by now one-fifth of the genes in your body are privately owned.

The results have been disastrous. Ordinarily, we imagine patents promote innovation, but that's because most patents are granted for human inventions. Genes aren't human inventions, they are features of the natural world. As a result these patents can be used to block innovation, and hurt patient care.

For example, Canavan disease is an inherited disorder that affects children starting at 3 months; they cannot crawl or walk, they suffer seizures and eventually become paralyzed and die by adolescence. Formerly there was no test to tell parents if they were at risk. Families enduring the heartbreak of caring for these children engaged a researcher to identify the gene and produce a test. Canavan families around the world donated tissue and money to help this cause.

When the gene was identified in 1993, the families got the commitment of a New York hospital to offer a free test to anyone who wanted it. But the researcher's employer, Miami Children's Hospital Research Institute, patented the gene and refused to allow any health care provider to offer the test without paying a royalty. The parents did not believe genes should be patented and so did not put their names on the patent. Consequently, they had no control over the outcome.

In addition, a gene's owner can in some instances also own the mutations of that gene, and these mutations can be markers for disease. Countries that don't have gene patents actually offer better gene testing than we do, because when multiple labs are allowed to do testing, more mutations are discovered, leading to higher-quality tests.

Apologists for gene patents argue that the issue is a tempest in a teapot, that patent licenses are readily available at minimal cost. That's simply untrue. The owner of the genome for Hepatitis C is paid millions by researchers to study this disease. Not surprisingly, many other researchers choose to study something less expensive.

But forget the costs: why should people or companies own a disease in the first place? They didn't invent it. Yet today, more than 20 human pathogens are privately owned, including haemophilus influenza and Hepatitis C. And we've already mentioned that tests for the BRCA genes for breast cancer cost \$3,000. Oh, one more thing: if you undergo the test, the company that owns the patent on the gene can keep your tissue and do research on it without asking your permission. Don't like it? Too bad.

The plain truth is that gene patents aren't benign and never will be. When SARS was spreading across the globe, medical researchers hesitated to study it — because of patent concerns. There is no clearer indication that gene patents block innovation, inhibit research and put us all at risk.

Even your doctor can't get relevant information. An asthma medication only works in certain patients. Yet its manufacturer has squelched efforts by others to develop genetic tests that would determine on whom it will and will not work. Such commercial considerations interfere with a great dream. For years we've been promised the coming era of personalized medicine — medicine suited to our particular body makeup. Gene patents destroy that dream.

Fortunately, two congressmen want to make the full benefit of the decoded genome available to us all. Last Friday, Xavier Becerra, a Democrat of California, and Dave Weldon, a Republican of Florida, sponsored the Genomic Research and Accessibility Act, to ban the practice of patenting genes found in nature. Mr. Becerra has been careful to say the bill does not hamper invention, but rather promotes it. He's right. This bill will fuel innovation, and return our common genetic heritage to us. It deserves our support.

Michael Crichton is the author, most recently, of the novel "Next."

[Copyright 2007 The New York Times Company](#)

[Privacy Policy](#) | [Search](#) | [Corrections](#) | [RSS](#) | [First Look](#) | [Help](#) | [Contact Us](#) | [Work for Us](#) | [Site Map](#)
