The Dawn of Genome Trolling

Massachusetts Institute of Technology

Last week European scientists were shamed into cutting off public access to a genome sequence. As far as I know, it's the first instance of a genome pulled from the public record.

It's also a bad precedent.

The case involves a line of cervical cancer cells, known as HeLa. As told in the book *The Immortal Life of Henrietta Lacks*, a bestseller by reporter Rebecca Skloot, the HeLa cell line came from the body of Henrietta Lacks, a poor African-American tobacco farmer. The cells were collected without Lacks's knowledge, and later researchers did even more dodgy research involving her children.

Lacks died of her cancer in 1951, but HeLa went on to become a big deal in science. In fact, it is the "most widely used model cell line" for studying human biology. That's according to some German researchers who, on March 11, decided to expand that knowledge by publishing the HeLa genome [1].

The publication set off a tizzy of criticism online, tracked here [2] by researcher Jonathan Eisen. Although no law required the Germans to ask permission from Lacks's family, it seemed in very poor taste not to have done so, especially given the notoriety of the case. Eventually Skloot, whose book is being made into a movie by Oprah Winfrey and HBO, got involved. She briefed the Lacks family and conveyed their concerns to the scientists, who then agreed to put a block on the data.

Source URL (retrieved on *10/23/2014 - 6:12am*):
http://www.mdtmag.com/news/2013/03/dawn-genome-trolling

Links:
[1] http://www.g3journal.org/content/early/2013/03/11/g3.113.005777.full.pdf
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