



2013 HAWAII UNIVERSITY INTERNATIONAL CONFERENCES
ARTS, HUMANITIES, & SOCIAL SCIENCES
JANUARY 6TH TO JANUARY 8TH
ALA MOANA HOTEL
HONOLULU, HAWAII

WHAT SOMETHING MIGHT MEAN: MYRIAD GENETICS, BIOETHICS AND THE SENSE OF STORY

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“The facts don’t speak for themselves.” This dictum was a familiar refrain in a US diplomatic history course I took as a young university student in the early nineteen-seventies. Narrative hadn’t yet acquired the intellectual or ideological currency the term now enjoys, but embedded in the professor’s simple, and perhaps self-evident, truth is the principle that a narrative doesn’t present itself fully-formed, with a neat arc that can be easily and irrefutably plotted, and with a fixed set of lessons that should be obvious to any careful observer. It is often difficult to remain mindful of the fundamental nature of narrative as artifice — as construct — whether the facts in question are geopolitical, or are associated with ethical issues in clinical or research domains. In my own work, which is primarily devoted to the construction of bioethics narrative, recognizing the extent to which a narrative is revealed through or occulted by the facts is a fundamental challenge.

This paper examines the ethical imperatives that attend the construction of a bioethics narrative; and details via case example the process by which an apparently straightforward intellectual property litigation reveals itself to be considerably more, with a plethora of implications (and complications), depending upon which ethical perspectives are brought to bear upon the interpretation of events. In the spring of 2011 my bioethics class engaged *Association for Molecular Biology, Et Al., vs. United States Patent and Trademark Office, Et Al.*, also known as the Myriad Genetics Case. At the time, an appeal was in process to challenge the ruling that had invalidated Myriad Genetics, Inc.’s claims to patent protection for (1) the discovery and isolation of a gene associated with breast cancer (BRCA1) and another associated with ovarian cancer (BRCA2); and (2) for the laboratory protocols to diagnose the trait. But the facts as argued by the litigants for either side were on matters of law, the extent to which additional research (which could improve diagnosis and treatment) was hampered or facilitated by Myriad’s proprietary claims, return on investment of venture capital, even the constitutionality of said patents, and other arguments having essentially to do with appropriate business and/or research models. In such an instance as this, the ethics of fiduciary responsibility to investors might well be irreconcilable with a physician’s duty toward a patient with a potentially life-threatening illness.

The bioethics narrative as construed by the class, and the case study the class subsequently created, derived from a consideration of health crisis as healthcare crisis: a young mother whose diagnosis of breast cancer was only the beginning of a cascade of devastating revelations, from wondering if her illness was genetic, to fearfulness that her six-year-old daughter was at risk, to learning that her insurance wasn’t accepted by the only available lab that was licensed to test her for the gene. This was to our perspective the central thread, even though it was for the most part obscured by the essential questions the court was asked to consider. Even so, when the task is to build a case study derived from the central narrative, careful scholarship demands that the finished product

be as free of inherent bias as possible. There is still an obligation to carefully consider — and to represent in as unbiased a manner as possible — the different lines of argument, even if one is, for example, disposed to regard the Myriad Genetics case as a biomedical example of what political journalist and author Naomi Klein calls “disaster capitalism.” One of the outstanding advantages of building case studies according to a Platonist (i.e., inspired by the Platonic Dialogues) model is that the strategy allows for the co-existence of competing narratives, without a prefabricated conclusion (or, for that matter, any obvious conclusion at all). This paper explicates the both the method and the ethical considerations that informed the creation of a bioethics case study, titled “Camera Obscura,” based upon *Association for Molecular Biology, Et Al., vs. United States Patent and Trademark Office, Et Al.*, the background details for which were most often reported not in a health or ethics context but as business and/or financial news.