

Tech Flesh 9: The Secret History of Jessie Gelsinger's Death

From the Manhattan Project to the Human Genome Project

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"**The Alta meeting** is thus the bridge from DOE's (Department of Energy) traditional interest in detection of mutations to [the] push for a Human Genome Initiative, and provides one of several historical links between genome projects and another massive technical undertaking of the 20th century--the Manhattan project."

Robert Cook-Deegan, from the DOE
webpage <http://www.ornl.gov/hgmis/project/alta.html>

When its discovery was first contemplated we were told that it was the "philosophers' stone" (because with it we could change what was thought immutable) and the "elixir of life" (because with it we might live forever). Normally reserved scientists were elated that through this new knowledge they would soon arrive at the secret to all creation. While occasion for such claims has most recently been the mapping of the human genome, the above sentiments manifest as well in 1889, when Marie Curie discovered radium.

While scientific breakthroughs often elicit hyperbolic enthusiasms, the similarities between the results of these two major investigative feats becomes even more intriguing when we begin to reflect on the significance of the Human Genome Project (HGP) being a direct descendant of Curie's radium research. According to government documents ranging from the DOE "Low Dose Raditation Research Program Timeline" (<http://www.lowdose.org/>) to the histories of the first funding of the HGP (www.ornl.gov/TechResources/Human_Genome), the key event responsible for research aimed at delineating human DNA fragments was the bombing of Nagasaki and Hiroshima. Hence the institutional home of the Human Genome Project is actually the Manhattan Project.

The Manhattan Project fell under the auspices of the U. S. Army Corps of Engineers, with most of the research being done in Manhattan, hence the name. While the Department of Defense and other security agencies support research on biological warfare, the study of the long-term effects of radiation poisoning was carried out by a civilian agency, first the Atomic Energy Commission (AEC) and now its successor, the cabinet level Department of Energy. The DOE was studying relatives of folks on the wrong end of a chain reaction set off to end World War II because the government

wanted to facilitate the use of nuclear energy, as well as continue research on nuclear bombs. Yet there remained a sticky problem of radioactive contamination. The government wanted to learn a lot more about how it affected us.

It is longstanding practice among reputable scientists not to use the results of Nazi studies, the thought being that it is indecent to retrospectively assign any usefulness whatsoever to the savage torture of helpless, blameless victims. Yet the AEC and now the DOE, to this day, use descendants of Nagasaki and Hiroshima survivors as human guinea pigs, with no worry that the victims of this wartime atrocity never signed subject consent forms. Through these studies, scientists found higher rates of leukemia than they would among those whose ancestors were not exposed to radioactive fallout, allowing them to make very rough predictions about the effects of exposure to low levels of radiation.

While scientists understood the descendants had a higher risk of leukemia, according to David Smith, a founder and former Director of the DOE Human Genome Program, "The program [to map the human genome] really grew out of a need to characterize DNA differences between parents and children more efficiently. DOE led the development of many mutation tests, and we were interested in developing even more sensitive detection methods." (<http://www.ornl.gov/hgmis/publicat/97pr/evolve.html>)

The idea to begin mapping the human genome was first mentioned in Alta, Utah. The DOE explains that "in 1984, at a meeting convened jointly by the DOE and the International Commission for Protection against Environmental Mutagens and Carcinogens, the question was first seriously asked: Can we, should we, sequence the human genome?"

The reason for the DOE to develop a map of the human genome was not to ascertain whether radiation was harmful. Human population studies, clinical evidence of radiation poisoning on individuals, and the large number of radiation studies done on mammals left no confusion on this point. In the face of this significant evidence, one might reasonably have thought that a group organized to protect against environmental mutagens and carcinogens, in a meeting with the DOE, might initiate discussions on how to limit environmental mutagens and carcinogens, as that is the best protection against them.

And yet the conversation over the four-day conference took a very different turn. Rather than address problems of radioactive wastes leaking from storage tanks into our air, soil and groundwater, the scientists (largely employed by the DOE-controlled laboratories at Los Alamos and Livermore) decided the correct object of intervention was the human body. Rather than clean up the environment, these scientists came up with the idea to clean *us* up.

"The ultimate goal" declared by the DOE on behalf of the HGP "is to exploit those resources [our DNA] for a truly profound molecular-level understanding of how we develop from embryo to adult, what makes us work, and what causes things to go wrong. The benefits to be reaped stretch the imagination." Indeed, especially if one is working on nuclear toxicities at the DOE. The anonymous writer, a cross between Dr. Strangelove and Disney's Tomorrow Land narrator, informs us that "even gene therapy will become possible, in some cases actually 'fixing' genetic errors."

As the DOE makes clear, genetic errors are not part of the human condition, but a consequence of the actions on the part of the DOE itself, which is responsible for the tritium that has leaked into the drinking water in Washington and is seeping into the Columbia River. Whether through direct consumption of water or the grapes, potatoes, apples and salmon in the area, the contaminants are already in the human food chain. As the DOE itself warns: "When present merely in low but significant amounts, toxic agents such as radiation or mutagenic chemicals work their mischief in the most subtle ways, altering only slightly the genetic instructions in our cells. The consequences can be heritable mutations too slight to produce discernible defects in a generation or two but, in their persistence and irreversibility, deeply troublesome nonetheless." A recent report written under the auspices of the National Research Council at the request of the DOE says current plans for nuclear wastes "will eventually fail" and that 30 percent of the billions of gallons of radioactive wastes are already leaking.

In 1904, 15 years after Curie's discovery, the "elixir of life" claimed its first canary. Clarence Dally, who was assisting Thomas Edison's research on X-rays, developed a malignant carcinoma. In 1999, 15 years after deciding that mapping the human genome could save us from the effects of radiation poisoning, Jesse Gelsinger was the first victim of gene therapy. Gelsinger, an 18 year-old with a rare liver disorder (one that was manageable with medicine) was injected with a virus, quickly developed a fever of 104 degrees, went into a coma the next day, and shortly thereafter died

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