## Bad Blood:

The Tuskegee Syphilis Study

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Website

In exploring topics for this year's NHD theme, "Rights and Responsibilities," we decided to learn about an event in history that interested us and displayed injustices pertaining to the theme. As first-generation Americans, we were fascinated with the issue of racism in minority history. Our common passion for science and ethics led us to settle upon the Tuskegee Syphilis Study.

To develop an overall understanding of the study, we began by exploring online databases and books. From there, we contacted several archives for collections of primary resources. We obtained copies of newspaper articles and government documents relevant to Tuskegee from the Cleveland Public Library. A librarian at the Library of Congress introduced us to an extensive online collection of photographs and papers. We also discovered primary materials from archives at University of Pittsburgh, Clinton Library, and Tuskegee University Library. After conducting research, we contacted potential interviewees for our project. We were fortunate to obtain a phone interview with Jean Heller, the Associated Press writer who exposed the study, as well as an email interview with Carol Yoon, the New York Times journalist who spoke with surviving Tuskegee patients regarding the aftermath of the study. Because of our proximity to Case Western Reserve University (CWRU), we were able to conduct interviews with Dr. Stuart Younger, chairman of the Department of Bioethics at CWRU, Dr. Dave Samols, Chairman of the CWRU Institutional Biosafety Committee, and Jennifer Scharf-Deering, Assistant Director of CWRU Research Compliance. We also spoke with Susan Reverby, author of *Tuskegee's Truths*, one of our most authoritative resources, and Dr. Christine Grady, Chief of the Department of Bioethics at the National Institute of Health and a member of the Presidential Commission for the Study of Bioethical Issues.

We decided early on to tackle the challenge of a website, which integrates components from the paper, documentary, and exhibit categories. As the Tuskegee study ended recently, only a website could effectively display the several multimedia materials available to us. Utilizing HTML and CSS coding, we incorporated interactive elements to enhance a reader's understanding of our project.

The Tuskegee Syphilis Study is entirely intertwined with rights and responsibilities, this year's NHD theme. The experiment was initiated in the early 1900s as a nationwide obligation and effort to cure venereal diseases. Moreover, the study was a fundamental violation of the right to informed consent, as patients were told that they had "bad blood," not syphilis. Syphilitic patients were also withheld from effective treatment and not informed of the necropsies that would be performed on them after death. Once penicillin became a viable remedy for syphilis, the Public Health Service still went to great lengths to ensure that patients were denied medicine. Despite these abuses, doctors continued the study for forty years, justifying their actions with the responsibility to achieve a discovery in an experiment that was never done before. Ultimately, the study's impact on bioethics attests to the nation's duty to protect its citizens from encroachment on their rights to informed consent.