

Live to Die: The Ethical Controversy of the Kalaupapa Leprosy Settlement

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## Process Paper

Of the many historical conflicts between rights and responsibilities, we chose the establishment of the Kalaupapa leprosy settlement because we wanted a topic in Hawaiian history that held relevance to our interest in medicine. We were inspired to take on Kalaupapa after seeing pictures of the patients advocating for their own rights. As aspiring doctors, we found this historical isolation to be influential as an example of a controversial decision that led to future discussions about ethical code and patients' rights.

We began our research by searching for motives and anecdotal accounts from both sides of the controversy to examine the opposing views of the government and doctors versus those of the patients. Using dissertations and reference books, we were able to confirm the historians' claims with primary sources we found from *Chronicling America*, the Hawai'i State Archives, and vertical files in the Hawaiian section of the Kamehameha School's Midkiff Library. Our exploration of Kalaupapa's history also exposed us to different research mediums such as songs, poems, and letters of the patients. We were also challenged to maintain balance between both arguments of our project. We found ourselves becoming empathetic with the patients who had been mistreated, but realized that we needed to recognize the pressure that had been put on the government to act in a way that would save lives. To accomplish this, we conducted interviews with Kalaupapa historian Anwei Skinsnes Law and Hawai'i Hansen's Disease Community Program manager Lori Ching for their analytic perspectives of the past and the present. This helped open our eyes to the complexity of the circumstances regarding medical segregation at the time. After the district and state competition, we added to this wealth of knowledge by interviewing historians Zita Cup Choy and Colette Higgins, UH Maui Professor Bud Clark, Executive Director of the King Kamehameha V Judiciary History Center Matt Mattice, Kalaupapa National History Park representative Timothy Jordan, and Louis Erteschik, the Executive Director at the Hawai'i Disability Rights Center, to explore the vast perspectives about the settlement.

We decided to present our project in the form of a website because it allowed us to incorporate interactive mediums such as videos, music, and pictures that enhance the project. Additionally, we discovered historical videos that support our claim, which alleviated some of the difficulty in staying within the word count for our analysis. The Hawai'i State Archives also had a plethora of photographs taken of actual patients that are extremely moving and help to set the solemn tone of our website.

The establishment of the Kalaupapa leprosy settlement is relevant to this year's theme because it summarizes the conflict between the decision to uphold the rights of the people versus the government's need to protect them. The patient's bill of rights and the new regulations that are now placed in dealing with epidemics reflect a historical change as a result of the Kalaupapa settlement, which highlights the restoration of balance between the rights and responsibilities in Hawai'i and America.

Word Count: 496