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Description and Explanation of the Research Process for *The Appalachian Dilemma: An Ethical Debate on Genetic Therapy and Genetic Enhancement*

The summer before coming to Eastern Kentucky University was the first time that I began exploring what I wanted to research for my Honors Thesis. I knew that I had to write a 30+ page research paper before graduating college, and it did not take very long before I was very aware of how little I knew about independent research. At the time, I was at a medical program learning about the importance of equity in health care and the unjust distribution of healthcare in Appalachia. I remember being instructed to find peer reviewed articles about the subject and having never heard of such a thing before then. Overwhelmed and confused, I asked many of my older peers to help teach me how to find peer reviewed articles online. After clumsily stumbling through some search engines and databases, I found a number of articles about the distribution of healthcare in Appalachia.

Instantaneously, I unknowingly ignited my passion for the just distribution of healthcare in America, and specifically in Appalachia. Soon after, I was in my first Honors classes at ECU, learning more about independent research from the first week of Honors Rhetoric than I had in all of high school. My class moved to the library for a couple of courses on how to use ECU Library's extensive databases, and how to utilize the "advanced search" option to retrieve more specific search results. This database became the main resource I utilized during my thesis research at ECU. After taking a number of writing intensive courses, I had written many research papers on subjects that I was interested in, but not subjects that I was incredibly passionate about. This was until I took Biomedical Ethics with my future thesis mentor Dr. Laura Newhart. In this

class, I revisited a subject that I had been introduced to at the International American Chemist Society Conference in San Francisco: genetic manipulation. In Dr. Newhart's class, I was given the opportunity to choose whatever biomedical ethical subject peaked my interest, was able to explore it further, and so I began my research on the ethics of genetic therapy and genetic enhancement.

In 2018, I completed my Honors thesis in 2 semesters. Although I knew what I was passionate about, combining all of my passions was tricky. I knew I wanted to incorporate my passion for medically underserved people in Appalachian with my interests in gene editing technologies and the ethical implications that accompany them. When I began the research process in the Spring semester, I utilized texts from Dr. Newhart's class, as well as the ECU Library Databases in order to really solidify my topic. My initial method was to find as many sources online using ECU Library's Databases that I could on all three of the topics I was interested in: healthcare in Appalachia, biomedical ethics, and genetic manipulation. Because each of these topics were pretty expansive, I became an expert at generating effective and efficient search terms to use in my advanced searches. Library Express was another tool that I utilized frequently during this first semester in order to quickly receive articles from outside sources.

Most commonly, any literature about genetic manipulation was in regards to the newfound science behind it all. Because the CAS-9/CRISPR gene editing system has only recently been discovered for the use of genetic manipulation, it was harder to find ethical policies on the subject. This is where my philosophy texts from my mentor were essential. I also asked a number of my professors in the ECU Chemistry Department for resources regarding CAS-9/CRISPR gene editing. Although the majority of the research was independent, Dr. Newhart

was a crucial resource. With her expertise in biomedical ethics, we found that there was very little literature on the effect that genetic manipulation will have on the future of Appalachia, the United States, and the world. This became the central idea of my thesis.

Aside from the resources I found through ECU Library Databases, Library Express, and the appropriate texts provided to me by my mentor, I also utilized TED Talks and other online lectures to solidify my topic and subtopics. I also found it incredibly helpful to utilize the bibliographies of some of my better sources and texts. This minimized time spent searching for related articles and allowed me to get familiar with what published bibliographies should look like.

As I began writing my thesis, I wrote in sections. This allowed me to focus on one subject at a time. My sources could each be separated into one of three topics: Appalachian healthcare, biomedical ethics, or gene editing/manipulation. Therefore, when writing my paper it was easiest to write in these subtopics first before intertwining them together. This also made the project seem much more achievable and prevented me from becoming too overwhelmed. With the resources available through ECU, I had no issues finding a vast amount of information regarding my rather specific and odd subject. I found that over the course of writing my thesis, I became a more efficient researcher and learned the importance of utilizing the staff at ECU for their expertise.