

Internship Report – Shawneequa Callier

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While at WHO I worked for the Human Genetics Unit and completed projects in WHO's Ethics, Legal and Social Implications (ELSI) of Genomics Program. I had the opportunity to work on a variety of projects including a comparative database I designed of international, national, and regional legislation, policy models, and statements that address four areas of genomics: genetic databases, genomic patenting, pharmacogenetics, and genetic testing. This project was particularly valuable to me because since the main task was to find out what "every country" is doing to address the selected ELSI in genomics issues, I

gained a deeper understanding of these issues, their impact on, and their current development in developed and developing countries. Class discussions regarding the ethical issues surrounding genetic testing and genetic databanks helped me to begin the internship with a sound background in the legal and ethical implications of genomics and therefore aided in my ability to identify relevant documents. Upon completion of this project I wrote a few paragraphs detailing my method of data collection. The method is likely to be published with WHO's final draft of its own international regulatory model. I am currently finishing up this report and a short bio about myself, in which I will mention my studies at Monash University. This bio will be published with the method.

Once this ongoing project of locating, organizing, and comparing regulatory documents was started and largely completed I began brainstorming questions that the human genetics unit might use to survey health ministers, academics, NGO 's, health professionals, and patients about how the selected ELSI in genomics issues are understood, addressed, and regulated in their respective countries. While creating this survey I reflected on our bioethics seminars in *Legal Issues in Bioethics* and *Questions of Life and Death*. After doing some research on how to write a good survey, I listed questions based on our discussions about *inter alia*: abortion and infanticide, prenatal sex selection, prenatal diagnosis and the disabled, procreative liberty, paternalism, patient rights, medical confidentiality, eugenics, institutional review boards and peer review, liberalism, communitarianism, and consequentialism. Resultantly, I designed two surveys of closed and open end ed questions that were both comprehensive and almost 20 pages long. My supervisor was impressed with the survey and asked me instead to organize the questions in database format so that she and other members of the department could analyze the questions and create a shorter though still comprehensive survey. If I had been able to afford a longer stay in Geneva, I might have helped more with the ethical document that Zara is providing as a background to the regulatory model that WHO is creating. Fortunately, however, I did take part in identifying articles that address ethical issues specifically, creating a booklist, and engaging in further discussion about these issues with Zara and the other intern with whom I worked.

The third major project I completed was a strategy report for the Online Genetic Resource Center which will connect experts, academics, and health professionals all over the world. It will provide up to date information on the following: genetic diagnosis, health service strategies, and genetic diseases;"best practices" guidelines to provide health professionals with tools for better management; and a space for dialogue and online training. Relying on my web-page and HTML knowledge, the insight I gained during my research on regulatory models, and the understanding I gained in our bioethics seminars about genetic and health services, I used a power point program to create a strategy report complete with diagrams that outlined how the human genetics unit might begin to structure and collect data for the Genetic Resource Center.

In all of these projects I worked independently with initial guidance from Zara. Zara never required me to work extra hours and was very sympathetic about my traveling to Geneva without proper financial support. However, I found the work so fulfilling and challenging that I enjoyed

working the hours that I thought were necessary to incorporate my bioethics background into comprehensive reports that I hoped would exceed Zara's expectations. Aside from my assignments, I attended a meeting at the United Nation's Human Rights Commission Office led by the UN Committee on the Rights of the Child. I also participated on the WHO's newly formed Ethics Council where staff members discussed how they are incorporating ethics considerations into their work regarding various aspects of world health. This opportunity to work with a UN agency allowed me to experience first-hand how an international organization serves the needs of developed and developing countries. It was particularly fulfilling to actually use one semester of coursework at Monash to uniquely serve WHO's needs. In addition, I attended various social functions and luncheons with interns and professionals working at other international organizations all over Geneva including the International Labor Organization and the United Nations. With my WHO badge I had access to seminars and public meetings at other international organizations and was able to begin conducting research for my Masters of Bioethics Research Paper at the United Nations library. While I believe I forged friendships with proactive individuals from different parts of the world, I was also inspired by many of the people I came in contact with. I believe I learned as much working at WHO and interacting with other interns as I learned in a semester of work at Monash. This experience contributed greatly to the enhancement of my career goals and my knowledge of Genomics issues. I am certain now that I would like to pursue a law degree and PhD in Ethics or Bioethics. I will also pursue further opportunities at International Organizations after I obtain these degrees. It would be wonderful if everyone pursuing a bioethics degree could participate in such a program.