

NTSAD Gottlieb Memorial Scholarships Essay

Joshua L. Greenberg

October 1, 2008

In the past year, I have seen the legacies of my brother and sister, Jonathan and Amy, continue to extend throughout my life. Following my initial efforts in the summer of 2007 to inform others of the gene patenting and conflict of interest case in which my parents and brother and sister were involved, in December of 2007 I was honored to speak at the Weill Cornell Medical College David E. Rogers Health Policy Colloquium, a weekly gathering of administrators, faculty, doctors, nurses, staff, and students.

I then interned in Weill Cornell's Office of Research Integrity this past summer, researching and developing new stem cell and tissue banking policies for the institution. My experience in the Office of Research Integrity surpassed my expectations, providing me the opportunity to gain firsthand insight into the system and processes through which institutions enforce the legal and ethical principles of research. In all of my work, I almost always returned to my family's case, as a stepping stone and medium of comparison in evaluating the pertinent ethical considerations in other cases. On a number of occasions, I found myself relieved and thankful to see the high standards in place at Weill Cornell and other institutions. On other occasions, however, I found myself frustrated with what I perceived as a policy shortfall – especially in addressing conflict of interest cases – not only at Weill Cornell but at comparable institutions as well. In particular, I have found the law to be rather ignorant in confronting these cases; I have begun to develop a number of legislative recommendations for encouraging better informed consent and improved oversight of conflicts of interest, and I hope to further develop these ideas in the future.

While at Weill Cornell, I was again honored to speak at a monthly meeting of the

Research Coordinators' Network, which consists of the staff members most directly tied to ensuring that scientific investigators follow all of the appropriate legal and ethical guidelines. Considering that the research coordinators are perhaps in the most practical position to bring about a difference in a researcher's adherence to ethical principles, I was particularly pleased to speak to them. Later, I gave a similarly gratifying presentation to a group of clinical research fellows as part of their "Responsible Conduct in Research" course.

Shortly before coming to Weill Cornell, I also had the opportunity to speak at the Annual Meeting of the Law and Society Association in Montreal. Here, I presented an article I co-authored over the past year with Michele Goodwin, the visiting professor at the University of Chicago for whom I conducted research in the summer of 2007. The article, which we entitled "Policing the Womb" and will be published in the *Cumberland Law Review*, investigates the legal and ethical implications of using pre-implantation genetic diagnosis for a rather unusual and unexpected ends: to deliberately select for disabled children. While this issue involves different ethical issues from those directly tied to my family's case, my brother and sister nevertheless shone through in my approach to the problem. As I wrote the paper, for example, I was forced to grapple with challenging questions, many of which remain unanswered in my mind. Is the purpose of medicine *always* to cure? Do disabled individuals live "unworthy" lives that justify the use of reproductive technology to eliminate disabilities? What will happen to diversity in society if we eliminate the disabled? Should some parents be permitted to select *for* disabilities, such as deafness, if they wish to counteract our society's inclination towards "anti-disability" and "anti-diversity"? In attempting to answer these many questions in my mind, my siblings provided an invaluable reference, as I speculated on their lives and disability, whether they were happy, and how life would have been without them.

While I have been significantly involved in these medico-legal-ethical areas, my ultimate interests remain in global health – although I see the two areas as far from disconnected. Indeed, the knowledge I have amassed on gene patenting and other forms of intellectual property has greatly contributed to my ability to analyze the oft-cited barriers to delivering essential medicines in the developing world. What strikes me as a constant in all of my endeavors is the pursuit of justice and fairness. What happened between Miami Children’s and my family arose from an abuse of power and information – the hospital dominant, the patients vulnerable: it was unjust. Likewise, many of the problems we observe in our world today – the absence of quality healthcare and education, the millions of people with HIV/AIDS, the *reason* they have HIV/AIDS in the first place – often arise from injustice and inequity in the general distribution of well-being. While the unfairness forced upon many of our fellow human beings throughout the world far exceeds the unfairness experienced by my family, I have nevertheless found striking analogies between their treatment in the have-have-not relationship and my family’s treatment in the doctor-patient relationship. Thus I approach these global health problems with an enhanced understanding of the issues at hand, and I shall continue fighting for fairness in all of the problems I encounter.