

NTSAD Gottlieb Scholarships Essay

Joshua L. Greenberg

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My brother and sister, Jonathan and Amy, both suffered from Canavan Disease. Over the course of my childhood, I watched them fade away. My brother died at eleven, and my sister at sixteen. Many people look at my family's situation and pity its severity. But I look at the situation and see many positives, though I certainly do not mean to say I am happy my brother and sister died.

For one, my experiences showed me how fortunate I am compared to so many other people. These people include the forty million suffering from HIV/AIDS. Without my brother and sister, I probably would not plan to research this disease, as I would not have seen firsthand the toll that diseases can take on individuals and families. To me, HIV/AIDS is the most devastating disease on the planet, in terms of both consequences and scope, and the greatest challenge in medicine at this time. The disease has existed since the early 1980s, the virus constantly mutates, and scientists remain stumped about a cure. In this challenge, I see the potential to make groundbreaking scientific advancements and to contribute to the betterment of many lives. Dr. Matalon, the geneticist my parents motivated to research Canavan, inspired me to tackle such goals. In him I saw a generous man who dedicated his career to intellectual exploration and community service. I wanted to be that type of person, and I still want to be that type of person.

My image of Dr. Matalon changed, however, in 1997, when my family learned that Miami Children's Hospital, where Dr. Matalon worked, had patented the Canavan gene and was charging royalties on gene carrier tests and potentially limiting research on Canavan, all without informing my parents or any of the other participants in the research. My parents and the other

participants were the key contributors to the research, donating so much of their tissue, urine, money, and time, all for the purpose of easing others' lives. Similarly to many other people, I viewed this ordeal and shook my head in disgust. Soon, however, I began to see positives. On a personal level, I now know of the dangers of gene patenting. Originally, I vowed never to patent any genes I may discover. I have since decided to patent all of them and donate them to the public good, so as to protect them from the greedy. I want to strive toward a science of freedom and cooperation in which everyone can pursue their goals and have opportunities to help others, not a science of egos and money in which people betray altruistic efforts and attempt to halt wonderful progress. As Jonas Salk asked, "Who owns my polio vaccine? The people! Could you patent the sun?" My goals to impact the state of science are already underway. Recently, I accepted an opportunity to speak on gene patenting at a Chicago-Kent College of Law conference. This experience prompted me to conduct research this past summer on topics regarding the ownership of the body under a law professor at the University of Chicago. While working there, I also accepted an opportunity to share my family's story and my thoughts about conflicts of interest with a class of fellows.

I never imagined Jonathan's and Amy's lives would have such significant impacts on medical ethics, with my family giving the fight against gene patenting some of its first national and international publicity. I am equally impressed with Jonathan's and Amy's extraordinary contributions to medical research. They paved the way for the discovery of the defective gene, the development of the gene carrier and prenatal tests, and the beginning of research for a treatment. Without my brother and sister, another family would be experiencing what mine did. Why should that happen?

I remember the great opportunities my brother and sister provided to medical ethics and

scientific research, and I have come to see challenges not as difficulties, but as opportunities.

Many people see the possibility for opportunities in “negative” situations as counterintuitive, but

I have learned through my experiences that these opportunities are quite realistic. Thus, I shall

enter the fight against HIV/AIDS to take advantage of opportunities, with the realistic hope that I

will help find a cure for its forty million victims.

Résumé

Current Involvement

- Nourish International
- Engineers Without Borders
- Engineering World Health
- Student Programming and Advisory Committee of DukeEngage

Past Accomplishments/Activities

- Guest speaker/presenter at the University of Chicago MacLean Center for Clinical Medical Ethics fellows course on Research Integrity under Dr. Mary Simmerling (August 9, 2007)
- Conducted medical legal research under Professor Michele Goodwin of the University of Chicago Law School (Summer 2007)
- Speaker/panelist at Chicago-Kent College of Law Conference entitled “Who Owns Your Body? Legal and Social Issues in Michael Crichton’s Next.” Spoke alongside Michael Crichton and a number of legal and ethical experts. (May 21, 2007)
- St. James Hospital (Olympia Fields, IL) emergency room volunteer greeter (Summer 2006 and 2007)
- Retinal prosthesis research under Dr. John Hetling at the University of Illinois at Chicago (Summer 2006)
- High school valedictorian, National AP Scholar, National Merit Commended Student
- Captain of high school debate team
- Qualified for high school policy debate National Tournament of Champions (2006-2007)
- 2nd place in Illinois State Policy Debate Tournament (2007)
- Received 16th (out of 208), 5th (out of 126), 15th (out of 220), and 15th (out of 364) speaker awards at four national debate tournaments (New Trier, Dowling, Emory, and Harvard, respectively – 2006-2007)
- Founder of debate team ad book fundraiser, the most successful fundraiser in team history (2006-2007)
- Attended debate camp during three summers (2004, 2005, 2006)
- Served as Senior Vice President of Barney Ross AZA Jewish Youth Group – responsible for programming and planning all events (2006-2007)
- Player on high school tennis team
- Caddie at Ravisloe Country Club (Homewood, IL), attained level of Honor Caddie