

NTSAD Gottlieb Memorial Scholarships Essay

Joshua L. Greenberg

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Over the past year, the organization I co-founded and direct, Progressive Health Partnership (PHP), has continued to grow. In 2009, PHP began the Safe Motherhood Initiative (SMI) in southwestern Uganda, which aimed to address rampant levels of maternal and infant mortality and morbidity by providing prenatal services to pregnant women in our two partner communities, Kashongi and Kitura. The SMI delivered health education, physical examinations, ultrasound scans, medications, and insecticide-treated bednets to prevent malaria. As we also conducted an extensive community-based needs and assets assessment through a survey and focus group discussions, we learned of the many challenges community members face in attempting to live healthy, fruitful lives. Access to safe water stood out as one of the most significant needs. In response, we began developing plans for a rainwater harvesting program based on the community members' suggestions. With \$180,000 in funding that I helped secure, we launched the program this past summer, installing 20,000-liter rainwater harvesting tanks at 37 public buildings throughout Kashongi and Kitura. The construction of the tanks was accompanied by a water, sanitation, and hygiene education campaign led by community members. At the same time, we continued the SMI, making steady improvements in the quality of care we provided.

Coordinating all of these efforts and planning PHP's long-term operations has been a challenging task. It has required hundreds of hours of time and many sleepless nights. However, I don't mind one bit. I stay awake because I am intensely committed to the people we're serving – because I cannot rest peacefully until the day I know that the citizens of Kashongi and Kitura, and all other marginalized parts of the world, enjoy the same level of human rights and

opportunities as I do. I sometimes ask myself what the source of my intensity is. Although I could point to a number of origins, I always return to my brother and sister, Jonathan and Amy, who were afflicted with Canavan Disease. The experience of watching Jonathan and Amy die has infused me with an imperative to prevent such tragedies from befalling others in this world.

The experience has not only provided the source of my motivation but has also crucially shaped my approach to the issues I am addressing. First, the betrayal my family experienced in the ordeal over the Canavan gene patent taught me countless lessons in research ethics and, more broadly, matters of justice. Given PHP's efforts to approach problems with a joint service and research perspective, my past experience has been invaluable. This past summer, for example, as I stood in the shoes of a researcher while I conducted an evaluation of PHP's rainwater harvesting project, I had a natural understanding of the ethical complexity of the research process. Although I see research as a critical component in strengthening our services – just as research was critical to developing testing for Canavan and will be critical to developing a cure – I am also able to appreciate the bigger picture and recognize the steps we must take to properly manage research in the context of serving a vulnerable population. In all my work in Uganda, I strive to treat people with the utmost respect and dignity, and my ability to make an impact is predicated on my ability to build trust between myself and the people I am serving. These qualities were fundamental lessons I learned from the years when my family itself was part of a population that was being served.

Second, the Canavan gene patenting case taught me that science is necessary but insufficient to solve the world's problems; for we also need sensible policies to establish a framework through which science can be actualized. Early in my college career, I devoted substantial energy toward advocating for a more open science, particularly in relation to my

family's experience with gene patenting. More recently, I have sought solutions to what I view as one of the greatest problems in global health today: the failure to deliver a handful of simple, proven, and inexpensive interventions – such as the tetanus vaccine or antibiotics for pneumonia – that would save the lives of millions of children each year. This challenge is fundamentally a policy question. The science to save these children's lives exists; but how do we translate it into reality? My pursuit of a global science of access and cooperation, which drove me to start PHP, is an extension of my earlier Canavan-related advocacy.

Perhaps most importantly, Jonathan and Amy instilled in me a resilience that keeps me forever focused on the task ahead. The perspective on life that I developed from growing up with them has taught me to navigate past the many bumps in the road. So when PHP's work in Uganda does not proceed as well as we would like, or when one of our grant applications is rejected, or when a fundraiser is not as successful as we hoped, I see beyond the disappointment and keep my eyes fixed on our long-term goals.

As I engage in these long-term goals and attempt to give the rural poor in Uganda a greater voice, I am also conscious of the lost voices of my brother and sister that I carry on. I live my life with a profound sense of responsibility to continue all of the good work Jonathan and Amy would have done, as well as a profound sense of privilege to have the opportunities I have been given. Indebted to this responsibility and privilege, I will never let down, I will never stop moving forward. I will always keep fighting to deliver high-quality healthcare in Uganda and around the world.