**Knowledge, Sensitivity, and HOPES**

by Albert Keung

*SURJ* is devoted to exploring original undergraduate field and laboratory research, but it also strives to highlight the real world, social, and personal implications of scientific research that are a consequence of academic exploration. The Huntington’s Outreach Project for Education at Stanford (HOPES) is a student-run website ([http://HOPES.stanford.edu](http://HOPES.stanford.edu)) founded to provide the public with accurate, scientific information about Huntington’s Disease in a manner comprehensible to the lay person. According to the HOPES website, Huntington’s Disease (HD) is a genetic disease that “causes deterioration of the nerve cells in the brain, prompting significant changes in one’s ability to think, feel, and move.” The primary mission of the HOPES team is to describe and explain the science behind this disease while remaining aware of sensitive HD-related issues. Unlike Stanford students involved in other research endeavors, the HOPES team focuses their efforts on reading research papers, understanding new studies on HD, and distinguishing between supported science and hearsay. After compiling the most current information, they tackle the difficult task of communicating the latest HD research in a clear and sensitive manner. The HOPES team strives to be responsive and mindful of the fear, frustration, and hope that mark the lives of those affected by HD. Their work demands strong literature research skills, clear writing ability, and, most importantly, sensitivity to those affected by the disease.

HOPES was founded in 2001 after Professor William Durham, the Bing Professor in Human Biology, Dept. of Anthropological Sciences, was contacted by a friend with a family member affected by HD. The family was frustrated at their inability to understand their doctor’s explanation and the scientific literature's explanation of the disease. Professor Durham emailed his friend back, breaking down the details of HD in his explanation. The family’s positive response to his email prompted Durham to create a widely available and comprehensive resource that individuals and families affected by HD could understand without needing a background in biology. With private funding and the support of the Human Biology internship program, HOPES was born. It is currently under the faculty supervision of Professors Durham, Joanna Mountain, and Ronald Barrett and is based in the Anthropological Sciences building.

The story behind the inception of HOPES gives just another example of how information, such as the term “genetic disease,” along with the vocabulary used in scientific literature, is incomprehensible to the majority of the world. HOPES’ mission is to break through the barrier of specialized language and provide accurate and scientifically rigorous information on HD in a style understandable to the common person. Professor Durham elaborates by saying, “We make no prior assumptions. We try to walk people from first premises. It makes [HD] less fearsome, less threatening to understand what’s behind [HD].”

In addition to the accessibility of HOPES’ language and information, the very nature of HOPES as an online resource is important, as realized by Melissa Schapiro, a HOPES senior majoring in biology and psychology. From her previous studies of autism and from talking to parents with autistic children, Schapiro found a “huge divide between what the scientific world knows and what the general public knows.” Furthermore, she learned that most parents did not read peer-reviewed research journals but instead relied heavily on websites and Internet discussion groups. Part of what motivated her to join HOPES was a desire to combat the distorted and often incorrect online information about medical conditions. Schapiro states that, “People deserve correct, unbiased scientific information that they can understand even if they don’t have a degree in science, or any college degree at all. HOPES provides a valuable resource to the Huntington’s community because it offers carefully researched articles.
that patients and their families can actually understand."

With its well-organized and easily navigable structure, the HOPES website reflects Schapiro's sentiments of accessibility. It includes helpful features like hyper-linked words in articles which can take the reader to glossary definitions or other web resources when clicked. Clear graphics help illustrate concepts like genetic inheritance and nerve cell biology. Interactive Flash components, like the "Brain Tutorial," further enhance the learning process by teaching through a storybook format with step-by-step illustrations. HOPES is also working to translate the website for non-English-speaking readers.

Internet technology is only one aspect of HOPES' approach to creating an informative yet accessible resource. The HOPES team also aspires to reach a broader audience, which includes young children whose parents or loved ones may have HD. Matt Stenerson, a former undergraduate student leader of HOPES, is currently working on a Flash online storybook called "For Kids," aimed at helping young children deal with the social and personal aspects of HD. "For Kids" tells the story of a child who is grappling with the social and emotional effects of having a father afflicted with HD. The story shows how education about HD empowers the child to deal with his feelings and the painful situation of having a family member diagnosed with HD. Stenerson also anticipates educational Flash games and puzzles in the future to help younger children learn about HD.

Stenerson, currently a HumBio course assistant, has been touched in many ways while working with HOPES. One of his most memorable moments was a late night correspondence with a woman whose husband had HD. Stenerson was surprised that she was still awake at 3 AM writing e-mails. She explained that she could only fall asleep each night by devoting her life to learning about HD and corresponding with others about the disease. The effect HD had on her and how it defined her life touched Stenerson and opened his eyes to the profound effects of the disease. He reflects that, "It wasn't just neurons and cells, but real people and families that were being affected by this disease." His aspiration to practice medicine was strengthened as he discovered the very personal, real world effects that HOPES and scientific knowledge have had in helping patients and their loved ones. Stenerson shared his feelings about HOPES and how it changed him: "It regenerated my hunger to achieve that goal [of being a doctor]. It gave me a real sense of worth, a feeling that I had actually put my education to good use."

Both the professors and the students working on HOPES identified numerous ways in which the project changed them. Beyond the academic learning in biology, epidemiology, and computer science, the HOPES students learn to distinguish hearsay and urban legends from peer-reviewed and supported science. They also develop teamwork and leadership skills from group interactions like peer-editing. Durham views the act of creatively collaborating and bouncing ideas off peers as an invaluable aspect of HOPES. Perhaps most important to Durham, students leave HOPES with a strong sense of responsibility and develop the maturity and ability to deal with delicate and complex issues in a sensitive way. "Knowledge is also responsibility," Durham said. "There is enormous responsibility to come face to face with these issues [involving HD], to explain the issues to the interested readership of the site, to not hide any issues, but to bring them up in a way that a painful message can be heard and appreciated and maybe rendered less painful by bringing it gently."

From the perspective of student experience, Durham views HOPES as a "kind of a prototype. It shows the kind of project students can direct and sustain, putting their education to work even as they are themselves working at that education." He also emphasizes the interdisciplinary nature of HOPES. He and the rest of the HOPES team believe students in any field can learn a great deal from working on the project and will contribute to an invaluable HD resource for the thousands affected by the disease. The HOPES team encourages interested students of all disciplines to visit the HOPES website for more information on how to join and contribute to the project.

Because of its many positive aspects, HOPES is a great example of what service projects can be. It provides a valuable and helpful resource for those affected by HD, and in creating this resource, students learn a unique approach to knowledge while simultaneously developing academically and personally. Team members graduating and leaving Stanford have been strongly influenced by their experiences in HOPES, and what they have learned will undoubtedly shape their future lives. The social impact of HOPES through both the website and its team members is immeasurable. As it gains broader notice, HOPES should serve as a paradigm for knowledge in action, applying science and education to benefit society.