



 **HUNTINGTON'S OUTREACH PROJECT
FOR EDUCATION, AT STANFORD**

Welcome to the HOPES Autumn Newsletter! The HOPES team has been working hard over the summer to present new articles, updates, and features to the website. To subscribe to future newsletters, please click [here!](#)



HOPES student researchers Caitlin and Natty interacted with HD community members at the Help 4 HD conference in August.

HOPESers Natty and Caitlin headed down to Southern California on August

22nd for Help4HD's 2nd annual symposium in Riverside, California. The symposium featured an array of guest speakers and presenters representing research groups, caregiver organizations, pharmaceutical companies, and advocacy groups. Keynote speakers included Dr. Donald Cleveland of UC San Diego, Dr. Leslie Thompson of UC Irvine, and representatives of the Inland Caregiver Resource Center and Riverside Community Health Foundation.

It was a day full of education, resources, and community for those who attended. For HOPES, the symposium was a wonderful opportunity to meet some of the dedicated individuals and organizations working to raise awareness and support for Huntington's disease and those that it affects. Student Researcher Caitlin Esparza thoroughly enjoyed the opportunity, saying, "the HD community is truly astounding in the amount of compassion and dedication individuals have for each other. I am grateful to have played even a small role in Help4HD's goal to create a world 'where everyone knows what HD and JHD is; a world in which compassion is a normal response to the devastation that this horrific disease [causes].'"

HOPES is eager to continue engaging with the HD community, and we look forward to attending more events in the future!

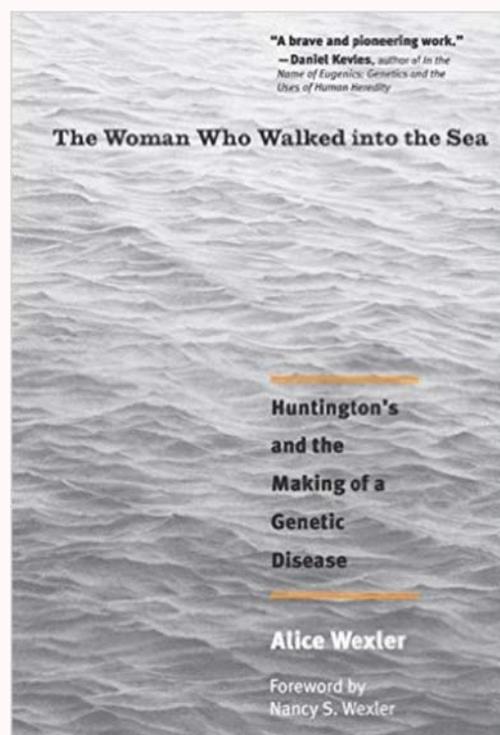


This past Saturday, the HOPES team had a chance to attend the annual HOPE Team walk organized by the HDSA in San Francisco. HOPESters Lina, Kristen and Annie along with HOPES advisor Bill Durham and son Drew Durham thoroughly enjoyed the opportunity to walk for the cause, meet other people passionate about making a difference in the HD community, and hearing the inspiring stories of individuals and families bravely facing the disease. HOPES tabled at the event, alongside representatives from the new [Stanford HD Center of Excellence](#).

The day's activities included opening remarks by HDSA board members, families affected by HD, and Dr. Veronica Santini of the Stanford HD Center of Excellence. The actual walk took participants along the water to a beautiful view of the Golden Gate Bridge, with volunteers holding encouraging signs along the way. The event ended with a silent auction to raise more money for HD. Representatives from various parts of the HD community showed up to support the cause, from researchers and physicians to patients and families. The walk was incredibly successful, and managed to raise over \$81,000 to help people affected by HD and their families.

If you would like to be involved in future events or volunteer with the HDSA, please check out [their website](#). If you want to be involved with the San Francisco chapter, please contact Natalie at ncarpenter@hdsa.org.

The most recent update to the literature corner of the HOPES website is a review of a book by Alice Wexler, sister of Nancy Wexler, the geneticist famous for discovering the Huntington gene. This book is a historical account of HD in America, and painstakingly documents the disease in East Hampton, Long Island families from its earliest historical appearance to the present. The book is rich with documents, and Alice Wexler grounds the history of HD through individual narratives and discussion of broader social



movements.

Wexler's very thorough book emphasizes how HD can be understood as part of "larger cultural narratives." She emphasizes that rather than dismissing the history as an example of bad science, we need to recognize that substituting scientific fact for superstition does not necessarily reduce stigma and prejudice. As we continue to search for treatment and a cure, constructing scientific knowledge in ways that benefit the HD community is tightly linked to our politics and priorities.

To read the full review of this book, please look at HOPEster Olivia Cords' [article](#) on the HOPES website.

HOPES Website Feature

The spotlight of this newsletter is on the HD [Stories of HOPES](#) section, which HOPEsters Natty and Caitlin have been expanding.

JHD Short Story Series is a series of fictional short stories from the perspective of someone with JHD. These works do not represent the experience of any one individual, nor do they aim to encompass the entirety of an illness experience such as JHD. Rather, these stories strive to capture and explore themes presented across different JHD and HD experiences through a collection of brief, episodic narratives. Hopefully, engaging with JHD through storytelling will allow readers to better understand this illness and empathize with those who have it.

Maladies of My Mind is a five-chapter fictional account of a surgeon in Thailand and how she struggles to come to terms with the possibility of carrying the gene for an incurable neurodegenerative disease in a country where mental illness is a stigma. This story is inspired by interviews of Thai individuals affected by different mental illnesses, but it does not cover the entirety of a Huntington's Disease experience in Thailand. However, it aims to explore themes of social stigma in a country where mental illness is stigmatized.

HOPES is a team of undergraduate students at Stanford University who, together with faculty advisors, are dedicated to making scientific information about Huntington's disease (HD) more readily accessible to the public. Our goal is to survey the rapidly growing scientific literature on HD and present this information in a web source. We seek to provide information about causes, symptoms, and treatment of HD that reflects current scientific understanding of HD. To date, HOPES resources have reached out to families in over 47 countries.

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