

UCSF and YouTube create novel channel to drive medical research

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YouTube, the online video community that allows people to discover, watch and share originally created videos, has teamed up with scientists at The University of California, San Francisco to tap the video sharing platform to drive medical research.

The move is the latest step by one of the world's leading cadres of neuroscientists to engage the general public and physicians in the fight against neurodegenerative diseases, while helping caregivers cope with these devastating illnesses.

The channel is intended to increase awareness among patients, their families -- and physicians -- about the various forms of dementia, with the goal of promoting earlier diagnoses and getting more patients into research studies and clinical trials. The site is also intended to educate caregivers, and provide support through caregiver testimonials.

To support the effort, the UCSF team is also reaching out with two other forms of online communication. They've created an electronic badge, or "widget," containing links to the YouTube channel and the UCSF Memory and Aging Center web site that will allow people to spread the word about the initiative via email and websites, including disease-education associations. They have also created a Facebook group, "Defeat Dementia."

"The YouTube channel and these other forms of online communications will enable us to engage a broad audience in the fight against these

illnesses," says Bruce Miller, MD, director of the UCSF Memory and Aging Center. "All of the dementias – including Alzheimer's disease, frontotemporal dementia, Creutzfeldt Jakob disease, Huntington's disease and Parkinson's disease with Lewy Bodies -- share common features. They all are illnesses in which normal proteins are misprocessed.

"One goal is to increase awareness about the earliest signs of some of the less well known diseases, including FTD and CJD. If we can promote accurate diagnoses of patients, we can get them into clinical trials sooner. We believe that early intervention with novel therapies will be key to stalling and halting these diseases."

The channel is the latest outcome of the "Fight for Mike," an initiative by Silicon Valley leaders to save the life of one man – former Apple Computer Inc. and Netscape Computer Corp. marketing wunderkind Michael Homer – that has broadened to a mission to advance scientists' understanding of Homer's rare, fatal illness, Creutzfeldt-Jakob disease. Understanding the disease, the UCSF scientists believe, will accelerate advances against the more common neurodegenerative diseases, including Alzheimer's disease.

Homer was diagnosed with CJD last spring and is being treated at UCSF. The Fight for Mike is led by two of his best friends, Silicon Valley investor Ron Conway and Intuit chairman William V. Campbell.

The idea to create the video-sharing channel, itself, resulted from a brainstorming session involving UCSF physicians and Silicon Valley entrepreneurs that was hosted last fall by YouTube CEO and co-founder Chad Hurley, a protégé of Homer's.

"Mike Homer is one of the great people to have helped build Silicon Valley," says Conway. "His extraordinary energy, creativity and passion helped drive the success of major companies and start ups. He also has

been a superb father, husband and friend. The Fight for Mike is intended to honor his spirit and drive the medical research underway at UCSF to cure CJD and related diseases. We're hoping the YouTube channel will support this effort."

The Fight for Mike, started last June, so far has raised more than \$7 million for CJD research at UCSF, where Stanley B. Prusiner, MD -- who was awarded the Nobel Prize in Physiology or Medicine in 1997 for discovering the protein, known as prion (PREE-on) that causes CJD -- leads a major research enterprise focused on all neurodegenerative diseases.

The funding has already had an impact on several fronts -- including the establishment of stable research funding for Homer's physician, Michael Geschwind, MD, PhD, a premier clinician-researcher on the diagnosis and treatment of prion disorders; the recruitment of Michael Silber, PhD, a former leader in the pharmaceutical industry, to establish a Drug Discovery program; and research strategies to identify new drugs.

The idea for the YouTube channel was an outgrowth of broad thinking.

The Homer family had experienced what others had before them -- the challenges of navigating the medical system to get a diagnosis of a relatively rare neurodegenerative disease and, later, implementing the necessary care-giving strategies in their home. A public forum dedicated to educating the public about all aspects of CJD -- and the other neurodegenerative diseases -- could address this need.

The decision was made to create a web page dedicated to CJD on the UCSF Memory and Aging Center website. A YouTube channel, the group proposed, could host video for the page as well as video on other forms of dementia, including FTD, Huntington's disease and

Alzheimer's disease. It could also serve as a portal to drive families and physicians to the UCSF Memory and Aging Center website for further information.

"I hope that the UCSF channel will provide scientists, researchers, and physicians a valuable communication tool as they search for solutions, and patients and their families another way to help cope with these tragic diseases," says YouTube's Hurley. "Mike is an inspirational friend, and I am grateful for the efforts that many have made in the quest to advance medical research of neurodegenerative diseases."

The "Fight for Mike" allocated \$200,000 for UCSF to hire a company to create the CJD site on the Memory and Aging Center website. It will serve as a template for the creation of disease-specific site on each form of dementia in the coming years.

The CJD web site, which will launch timed to the YouTube debut on June 16, includes UCSF physician-researchers and nurses discussing CJD, information for caregivers, testimonials by caregivers, advice for physicians (infection control, interpreting tests, finding services); and the science of proteins and prions (Nobel laureate Prusiner, protein models, scientific talks, lab procedures, etc.) geared to basic and translational scientists.

Source: University of California - San Francisco

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