

Calling out a 'silent killer'

Millennials initiate hepatitis B outreach campaign

Driving my boyfriend home from chemotherapy, we couldn't believe the ad on the bus in the next lane. We had to read it again at a red light.

The ad warned that one in 10 Asian Americans are infected with hepatitis B and don't know it — with a quarter of hepatitis B carriers at risk of dying from liver cancer or failure.

Nothing about my boyfriend's illness made sense until we saw that ad ...

At 30, Mark Lim was diagnosed with inoperable liver cancer caused by hepatitis B. He was fit, never drank and was symptom-free until the day he doubled over with excruciating stomach pain. A scan showed his liver riddled with tumors, seemingly out of nowhere.

Yet, Mark was Asian American. Why didn't his doctors know about the Asian Liver Center at Stanford University, the sponsor of the bus ad?

The Asian Liver Center was just a basement storage room converted into a cramped office, a symbol of how little the medical establishment had paid attention to hepatitis B in Asian Americans when we visited in 2001. The director, Sam So, was a renowned liver transplant surgeon on a mission to end an epidemic of hepatitis B. He called it a "silent killer" of Asian people worldwide.

Today, the center So started has its own building on the Stanford campus, and a new generation of activists, including So's son, has joined the cause.

"Mark Lim could be me or one of my friends," said Richard So, 30, who first heard Mark's story as a teenager and often tells it in presen-

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tations. "Mark could be any of the software engineers from China or Southeast Asia riding the tech bus to Silicon Valley right now."

Asian and Pacific Islanders (APIs) represent more than a quarter of the Bay Area population, and 35 percent of San Francisco. Despite nearly 20 years of public education and political advocacy around hepatitis B, too many young people like my late boyfriend are still dying.

That's why Richard So and his colleague Arcadi Kolchak, 31, are reimagining a decade-old "Hep B Free" campaign that began in San Francisco. They want to expand it throughout the Bay Area to reach the APIs most at risk: immigrants at all ages and U.S.-born millennials at every socioeconomic level.

Meanwhile, Richard's father is focused on an international solution by working with the World Health Organization, multinational companies and countries like China, where hundreds of millions are infected. The goal is global elimination by 2030.

UNDERSTANDING HEPATITIS B

Hepatitis B is widespread in many Asian countries. It didn't matter that my late boyfriend Mark was born and raised in an upper-middle-class suburb of Chicago, where the rate of hepatitis B was near zero. His

mother was born in China and lived in the Philippines, where the virus is rampant. She contracted it long before moving to the United States and passed it to Mark at birth.

Hepatitis B is especially insidious because it is 100 times more infectious than HIV and is often transmitted from infected mothers to their newborn babies. Even sharing a toothbrush contaminated by the blood of an infected person is a possible culprit.

Adults that contract hepatitis B frequently get sick, but the vast majority will eventually recover. It's a different story for infants and young children; they're more likely to develop a life-long chronic infection without any symptoms. The virus is "silent" because it can reside in the liver for decades before causing any damage. Mark died of liver cancer at 31 because the clock started ticking on his disease the day he was born.

The good news is that a vaccine exists to prevent new hepatitis B infections, and all newborns in the U.S. today are recommended to be vaccinated. For those already carrying the virus, antiviral medication is an option. Regular monitoring can also detect liver cancer early when treatment can be successful.

Yet, too many people with mothers from API and Southeast Asian countries still don't know they need to get tested for hepatitis B and monitor their liver if they have a chronic infection. Mark, for example, became a victim despite access to the best medical training and counsel. He was a young doctor who completed his residency at a prestigious teaching hospital. Required



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Arcadi Kolchak, left, and Richard So are millennials working to save their generation and others from an epidemic of hepatitis B in the Asian and Pacific Islander community.

blood tests showed he had hepatitis B, but the director of infectious diseases told Mark not to worry about it until age 50, never considering the possibility Mark had been infected since birth and at immediate risk.

SOUNDING THE ALARM

To get his message out of the Stanford basement, Sam So raised funding through his friends in the Bay Area and Asia. He partnered with people who understood marketing and communications better than a surgeon. He also leveraged the API community's growing political influence and ability to advocate for itself.

So started "San Francisco Hep B Free" in 2007 with politically connected publisher Ted Fang. Other co-founders included Janet Zola of the San Francisco Department of Public Health and Stuart Fong of Chinese Hospital. Popular elected official Fiona Ma joined the cause after announcing she had hepatitis B.

When Fang's Asian Week Foundation stopped running "Hep B Free" in 2014, community leader Caryl Ito helped identify and mentor the next generation to manage the awareness and testing campaign.

"Caryl is a hero. Even though she lost her brother to liver cancer, she has saved many lives with all the time and energy she devotes to Hep B Free," said Kolchak, the initiative's new executive director. "Taking over an organization with a mission this important was frightening, but Caryl trained me well and is always on my case to do better."

A NEW DIRECTION

Kolchak renamed the group "San Francisco Hep B Free — Bay Area" and his first hire was Richard So to lead the San Mateo operation. They became friends while college interns on a local political campaign. Richard urged Kolchak, whose mother is

from South Korea, to get tested for hepatitis B.

"He told me the Mark Lim story and that's what inspired me to dedicate my career to fighting hepatitis B," said Kolchak, who earned a master's in public health while working for an elected official in Santa Clara.

Richard So has the same degree and worked for a member of the state assembly. Together, they are using their political experience and knowledge of health policy to run a savvy campaign aimed at millennials.

The timing is critical: While hepatitis B testing of pregnant women and vaccination of infants became U.S. policy in the late 1980s and early 1990s, it took several more years to become standard care. That means people born in the U.S. before 1995 — millennials in their mid 20s and 30s — are at risk if their mothers were born anywhere in Asia or the Pacific Islands.

Kolchak and So also need to reach, educate and test the constant stream of immigrants from China and other API and Southeast Asian countries coming to work in Silicon Valley. They are all at risk, regardless when they were born.

No single message will save everyone. Kolchak and So are trying to reach multiple audiences that are immigrant, U.S.-born and at every income level. Success depends on how to talk about the issue and where to offer testing.

Kolchak and So have a daunting task, which includes raising the funds to keep it all going. But there is a sense of progress that provides inspiration. The bus ad my boyfriend and I saw announced that one in 10 Asian Americans have hepatitis B.

Today, the number is one in 12.

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