Surviving Still

Jesús Guillén fights for HIV long-term survivors.

September 24, 2018 By Alicia Green

Jesús Guillén left behind everything he knew and loved in Mexico to immigrate to the United States in 1984. A year later, he tested positive for HIV.

“I felt like I needed to move somewhere else to keep learning in life,” says the HIV advocate and independent consultant, who lives in San Francisco. “I just took that risk.”

After his initial HIV test came back positive in 1985, Guillén got tested five more times before finally accepting his diagnosis.

Without family or a community to turn to for support, Guillén faced his condition alone for many years. But he never gave up.

Knowing how a lack of community can affect people living with HIV, especially long-term survivors, Guillén took action.

In 2015, he created the HIV Long Term Survivors group on Facebook, which has nearly 5,000 members and is open to everyone who identifies as a long-term survivor, including those diagnosed since the advent of effective antiretroviral treatment for HIV in 1996.

“My conception from the beginning was to open a group that was based on acceptance and inclusiveness and not on denial of whoever you are,” he says.

Guillén is incredibly proud of the diverse Facebook group, which includes women, transgender people, heterosexual men, men who have sex with men, and more.

He is also the cochair of San Francisco’s HIV and Aging Workgroup and a member of the Long Term Care Coordinating Council, which advises the mayor on policy pertaining to older adults and people with disabilities.

One of his many ambitions is to connect organizations for people living with HIV with those for older adults. “Most of us didn’t plan to have a life growing older, so we’re not prepared now,” Guillén explains. “We don’t have those resources.”

In 2016, Guillén was featured in the award-winning documentary Last Men Standing, which

chronicled the stories of eight HIV long-term survivors in San Francisco. He also appeared in the film's poster.

"I was the one representing this community with constant pain," says Guillén, who suffers from neuropathy. "I was representing the immigrants and Latinos."

A singer and composer, Guillén wrote the song "Surviving Still" to raise awareness of the plight of long-term survivors.

"We have to get out of the HIV bubble and talk to the world," Guillén says. "The world needs to know what happened after the early days of the epidemic and what happened to these people now growing older with HIV."

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